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An interpretative phenomenological analysis of the  
experiences of autism and perceptions of parenting in  
parents with a child with autism

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A thesis submitted for the degree of  
Doctorate in Clinical Psychology

School of Health in Social Science  
College of Humanities in Social Science

The University of Edinburgh

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## **Thesis Abstract**

### **An interpretative phenomenological analysis of the experiences of autism and perceptions of parenting in parents with a child with autism**

**Background:** Research has highlighted that parenting a child with autism can be challenging and stressful. However, many parents successfully cope with the challenges posed by autism. A systematic review investigated parental psychological predictors of positive adjustment and coping in parents with a child with autism. Although a range of potential predictor variables were examined, including social support, coping styles and religious beliefs, the results of the review were inconclusive due to the conceptual overlap of predictor variables, and inconsistent use of outcome indicators of positive adjustment. However, parental perceptions of their situation and themselves as parents were represented across a number of variables, and were thought to be of relevance in understanding processes of adjustment. Therefore, qualitative research was undertaken to explore this further.

**Method:** Semi-structured interviews were conducted with eight parents of children with autism on their experiences of being a parent, and their perceptions of influences on their sense of self. The data were analysed using interpretative phenomenological analysis (IPA).

**Results:** The following five super-ordinate themes emerged from the study: 'experiencing autism as hard to know', 'experiencing autism as all-consuming and extreme', 'diagnosis giving understanding and confidence', 'parenting in the eyes of

others', and 'dilemma of acceptance'. The meaning of these themes for parents and how they related to their sense of self and belief in their ability was discussed. For example, the ambiguity and difficulty in understanding autism, and the overwhelming nature of the condition related to feelings of self-doubt in parents. On the other hand, confidence increased when the diagnosis was identified, and when parenting skills and the child's progress were recognised by others.

**Discussion:** This research has provided a richer understanding of self-perceptions of parenting and the impact of these experiences on a parent's sense of self. It has contributed to a broader literature on positive adjustment in families with a child with autism. This understanding will be useful to those seeking to engage and support families with a child with autism, and assist parents with coping and adjustment.

**Notes:**

- For simplicity of reading, the term 'autism' will be used throughout the thesis, and refers to the range of autism spectrum disorders (ASD) including Asperger syndrome.
- The main body of the thesis will be formatted using the BPS Style Guide. However, the systematic review (Chapter 1) and the journal article (Chapter 4) will be formatted to the guidelines of the chosen journal, *Autism* (Appendix 12).

## **Chapter 1: Systematic Review**

This systematic review was prepared in accordance with guidelines for the journal *Autism* (Appendix 12).



**Psychological predictors of positive adjustment in parents with a child with autism:**

**A systematic review**

**Abstract**

*Background:* Research has consistently shown that parenting children with autism can be challenging and stressful. Studies have examined child and parental characteristics that contribute to this. However, many parents successfully cope. The present review examined parental psychological predictors of positive adjustment and coping in parents with a child with autism.

*Method:* A systematic review of the literature was conducted using pre-defined inclusion criteria, and the methodological quality of studies was assessed.

*Results:* Fifteen studies were included which examined a range of psychological predictors across a variety of indicators of positive adjustment. Studies varied in methodological quality, and some findings were contradictory. However, variables of sense making, social support, and coping strategies, and the relationship of these with religious beliefs were found to be predictors of positive adjustment and require further attention.

*Conclusions:* Agreement is needed on consistent measures of predictors such as social support and coping, as well as indicators of positive adjustment in order to further understanding in this area. This would assist in providing interventions to support positive parental adjustment.

### *Key words*

Autism, parents, adjustment, psychological well-being, systematic review

### **Background**

Research has shown that parents of children with autism report more stress, depression and anxiety than parents of children with other developmental disabilities or health problems (e.g. Eisenhower et al., 2005; Hastings, 2008). This stress could in part be related to parenting a child with the core impairments associated with autism in the areas of social communication and interaction, and restricted interests, however, child behavioural problems associated with autism have been found to be more closely related to parental distress than autism symptom severity itself (e.g. Hastings et al., 2005). Barker et al. (2011) showed that over a ten-year period, child behaviour problems were associated with increasing levels of parental depression and anxiety. This effect has been physiologically validated by research measuring the relationship between daily cortisol levels in this group of parents and chronic child behaviour problems (Seltzer et al., 2010). Benson and Karlof (2009) suggest that stress proliferation can account for some of the variation in parental psychological distress in this population.

The contribution of parental characteristics to psychological well-being and levels of stress in parents has also been considered. Psychological characteristics examined in parents with children with autism include social support (e.g. Boyd, 2002); styles of cognitive appraisal, such as sense of coherence (e.g. Olsson and Hwang, 2002), locus of control (e.g. Siman-Tov and Kaniel, 2011) or self-efficacy (e.g. Hastings and

Brown, 2002); and coping strategies (e.g. Mancil et al., 2009). These have been variously examined as independent predictors, as well as mediators or moderators of the impact of child characteristics.

Until recently, research predominantly focused on predictors of negative mental health and psychological distress (e.g. levels of depression and anxiety). Davis and Carter (2008) identified that around half of the parents in their sample did not experience stress and coped successfully with their child with autism. Hastings et al. (2002) and Blacher et al. (2005) emphasised the importance of looking at positive as well as negative indices of adjustment, as there may be independent processes at work. Adjustment could be construed not just as absence of, or lower levels of distress, but through positive outcomes such as positive well-being or quality of life. Some indicators of positive adjustment refer to specific responses to difficult circumstances, such as positive adaptation (e.g. resolution of diagnosis); and positive growth (e.g. spiritual growth). The present paper reviews studies that explicitly and conceptually measure parental psychological predictors of positive adjustment and coping in parents with a child with autism.

## **Method**

### *Literature search strategies*

The search strategy was informed by international guidelines on systematic reviews by University of York's Centre for Reviews and Dissemination (CRD, 2008), with additional guidance on information retrieval from Petticrew and Roberts (2006) and Hammerstrøm et al. (2010).

*Inclusion and Exclusion Criteria.*

Included papers were quantitative studies of original empirical research published in English language peer-reviewed journals examining psychological predictors of positive adjustment in parents with a child with autism. Studies measuring both positive and negative adjustment outcomes were included, however only positive outcomes were reported.

Studies were excluded:

- if the outcome variable of adjustment was exclusively negative (e.g. mental health problems), was child-related rather than parent-related (e.g. child functioning), or was transient;
- if children of the parents in the sample did not have a diagnosis of autism, if the sample contained multiple diagnoses/disabilities, or if they were exclusively adult children.

Relevant social science databases were searched in February 2012 including:

EMBASE, PsycINFO, MEDLINE, CINAHL Plus, Applied Social Sciences Index and Abstracts, International Bibliography of the Social Sciences, ERIC, Social Services Abstracts and Sociological Abstracts. In order to maximise sourcing relevant papers, no date limits were set. However, all papers meeting criteria for this review had been published since 2000.

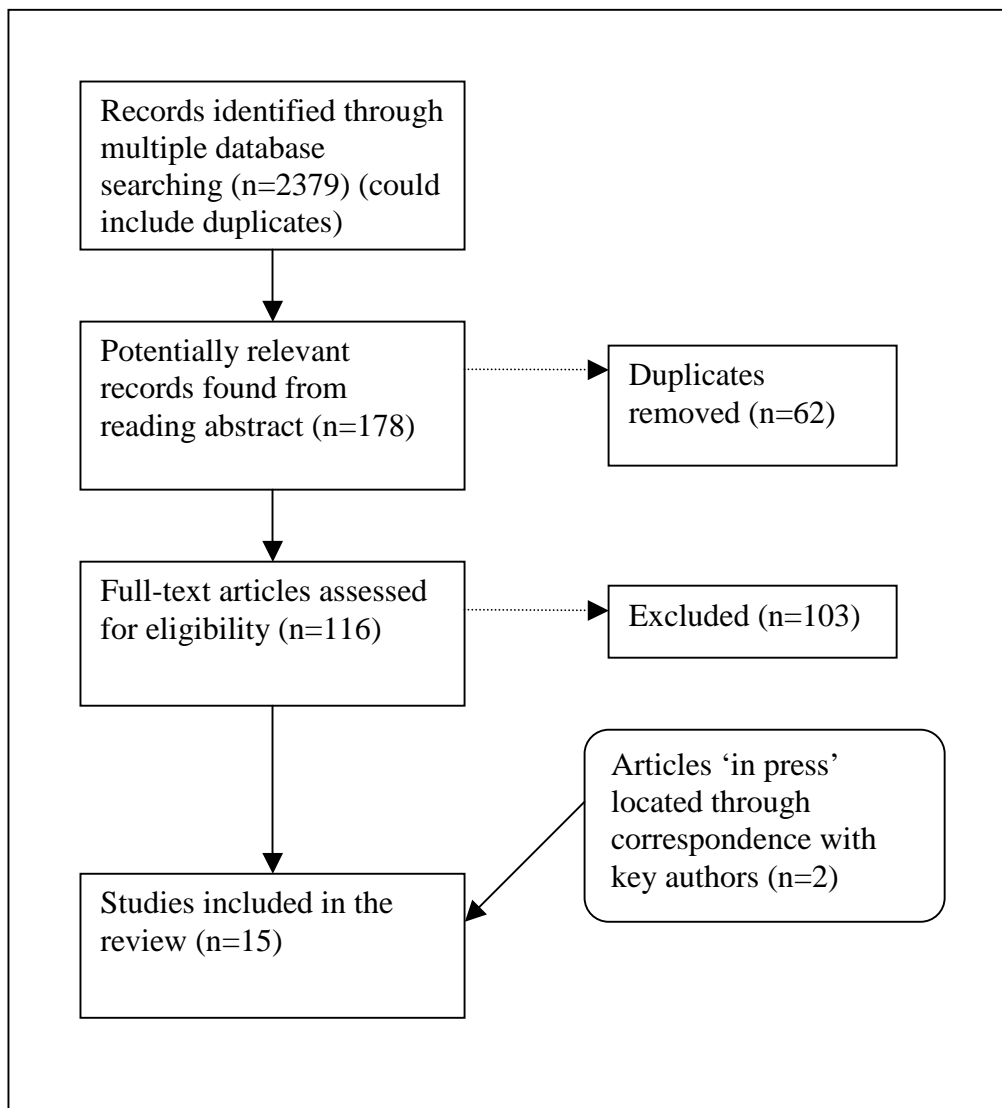
Search terms were broadly defined due to the range of terms in use for both positive adjustment and potential psychological predictors. Databases were searched using both free text and controlled vocabulary search terms. The following seed terms were used in an initial free text search and to generate controlled vocabulary or thesaurus terms for each database:

1. 'autis\*'
2. 'parent\*' or 'mother\*' or 'father\*'
3. 'coping' or 'adjustment' or 'adaptation' or 'resilience' or 'well being'
4. 1 and 2 and 3.

Following a search of the above databases, Social Sciences Citation Index on Web of Knowledge was used to find any articles that cited the included papers. In addition, the 'find similar' function was used to find any similar papers of the included studies, and bibliographies of the included papers were also searched. The Tables of Contents from five common journals of the included papers were searched by hand.

Corresponding authors who had published two or more included papers were contacted by email to identify any unpublished or pending research.

**Figure 1: Flow diagram for study selection**



*Study selection (Figure 1)*

The initial database searches resulted in 2379 potential papers being identified. An initial reading of the titles and abstracts indicated that 116 unique studies potentially met the inclusion criteria. These papers were read in full and 13 were retained for inclusion in the review. Two other articles that were 'in press' were obtained through correspondence with key authors in the field, bringing the total number of included papers to 15.

### *Assessment of quality of included studies*

No existing guidance for assessing the quality of non-intervention research on psychological predictors or risk factors for particular outcomes were found, so relevant criteria were devised through recommendations from Petticrew and Roberts (2006), Crombie (1996) and CRD (2008), particularly on those relating to questionnaire-based research. The ten criteria were chosen to assess the relative strength of the paper in reducing bias in terms of sample selection, reliability and validity of measurement tools, methodological and statistical issues and quality of reporting. The quality criteria for the current review included 10 items outlined in Table 2. A study scored 2 points if the principle was well addressed, 1 point if it was adequately addressed, and 0 if it was poorly addressed or not reported. As ratings were not weighted, the total score provided a guide to the methodological strengths and weaknesses of the studies, relative to the other included papers. Scores greater than 17 were deemed to be stronger papers and were labelled as ‘good’, scores between 12-16 were of average quality and labelled as ‘fair’, and scores below 11 were methodologically weak and labelled as ‘poor’.

## **Results**

### *Characteristics of included studies*

Details of study characteristics and key findings of the 15 included studies are presented in Table 1.

**Table 1: Description of studies included in the review**

Author	Relevant research aims and objectives	Design/ Method/ Analysis	Sample Parent	Sample Child	Measures of positive adjustment	Psychological predictor variables	Relevant findings to research question	Quality criteria score
<b>Positive Well being</b>								
Smith et al. (2011) USA	How size and valence of social support networks predicts maternal well-being	Longitudinal Questionnaires Regression	269 mothers mean age =52.35.	Mean age=23.15 (range 11-50, 74.7% male)	Positive affect (PA: Profile of Mood States)	Social support: network size, positive support and negative support	Network size predicted increase in PA. Negative support predicted decrease in PA and positive support was not a sig. predictor	Fair
Ekas et al. (2010) USA	Relationships between optimism, social support and maternal well-being	Cross-sectional Questionnaires Structural equation modelling; regression	119 mothers mean age =40.13.	Mean age=9.45 (range 2-18, 82.9% male)	Positive affect (Positive and Negative Affect Scale; PANAS) Satisfaction with Life Scale (LS: SWLS) Psychological Well-being Scale (PWB)	Social support: family, friends and partner Optimism (Life Orientation Test; LOT) Parenting Stress Items Scale (adapted)	Family support associated with higher optimism, which is related to high PA, LS and PWB. Friend support directly linked to PA, partner support with LS and PWB	Fair
Ekas et al. (2009) USA	Role of religious beliefs, religious activities and spirituality in maternal socio-emotional functioning	Cross-sectional Questionnaires; Hierarchical regression	119 mothers mean age =40.13.	Mean age=9.45 (range 2-18, 82.9% male)	Positive affect (PANAS) Satisfaction with Life Scale (SWLS) Psychological Well-being Scale (PWB) Optimism (Life	Religious beliefs Religious activities Spirituality	Higher religious beliefs predicted higher self-esteem and optimism when other variables accounted for. Religious activities predicted lower SE, PWB, PA, and internal sense of control.	Fair



					Orientation Test; LOT) Child-related Enjoyment Sense of control (Personal mastery and Perceived constraints) Self esteem (SE: Rosenberg SE Scale)		Spirituality predicted higher SE, LS, PA, PWB and internal sense of control.	
Samios et al. (2011)  Australia	Effect of own and partner's benefit finding and sense making on adjustment	Cross-sectional Questionnaires Correlation APIM (Actor-Partner Interdependence Model)	84 dyads N=168 mean age mother=41.83, father=44.33	Mean age=10.63 (range 6-16, 85% male)	Positive affect (Bradburn Affect Balance Scale) Satisfaction with Life Scale (SWLS) Dyadic Adjustment Scale	Global Benefit finding (BF: Benefit Finding Scale for Parents with a Child with Asperger Syndrome; BFS-PCAS) Sense making (SM: Sense Making Scale for Parents with a Child with Asperger Syndrome; SMS-PCAS; 6 factors) (both for Actor and Partner)	SM and BF not independent in dyads. Mothers – 'reframing' (SM subscale) related to better PA. Partner effect of mother's 'changed perspective' (SM subscale) significant predictor of father's LS. Global BF not related to PA.	Fair

Samios et al. (2009)  Australia	Role of benefit finding in adjustment	Cross-sectional/ Longitudinal Questionnaires Correlation Regression	220 parents (131 mother, 88 fathers, 1 unknown) mean age mother=41.75, father=44.88.	Mean age=10.72 (range 5-18, 85% male)	Positive affect (Bradburn Affect Balance Scale) Satisfaction with Life Scale (SWLS)	Benefit finding: Global benefits and 6 subfactors (BFS-PCAS)	Global benefits related to PA, particularly 'growth in character' and negative 'greater understanding' subscales. 'Positive effects of the child' predicted LS. No longitudinal effects.	Good
Samios et al. (2008)  Australia	Role of sense making in adjustment	Cross-sectional/ Longitudinal Questionnaires Correlation Regression	218 parents (130 mother, 87 fathers, 1 unknown) mean age mother=41.75, father=44.87.	Mean age=10.72 (range 5-18, 85% male)	Positive affect (Bradburn Affect Balance Scale) Satisfaction with Life Scale (SWLS)	Sense making (SMS-PCAS; 6 factors)	Sense making ('reframing') related to PA and LS. Longitudinally sense making does not predict adjustment	Good
Kuhn and Carter (2006)  USA	Predictors of maternal self-efficacy (associated with well-being and positive outcomes)	Cross-sectional Questionnaires; multiple regression	170 mothers, mean age=37.	Mean age=6.5 (range 2-10 years, 87% male)	Maternal Self-efficacy Scale	Maternal agency Maternal guilt Maternal autism knowledge	Maternal guilt negatively and maternal agency positively predicted maternal self-efficacy	Fair
<b>Positive Adaptation</b>								
Greeff and Van Der Walt (2010)  South Africa	Predictors of successful adaptation and resilience	Cross-sectional Questionnaires; multiple regression	34 families (mothers=24, fathers=4, unknown=6) mean age=36.21	Mean age=6.48 (range <10, 91.2% male)	Level of adaptation (Family Attachment and Changeability Index; FACI8)	Social Support Index (SSI) Relative and Friend Support Index (RFSI) Family Problem Solving and	RFSI, FPSC, passive appraisal as a coping style were significant predictors of family adaptation	Poor

						Communication Scale (FPSC) Family Hardiness Index (FHI) Family Crisis Oriented Personal Evaluation Scales (F-COPES) Family Time and Routine Index (FTRI)		
Kayfitz et al. (2010)  Canada	Relationships between positive experiences and stress in mothers and fathers	Cross-sectional Questionnaires Correlations	23 family pairs, N=46. mean age mother=38.70 father=42.17.	Mean age=7.39 (range 5-11, 83% male)	Positive Contributions survey	Parent distress subscale of Parenting stress Index	Negative correlation between positive contributions and parenting distress, i.e. higher reporting of positive experiences, lower distress	Fair
Pisula and Kossakowska (2010)  Poland	Relationships between sense of coherence and coping in autism and non-autism groups	Cross-sectional Questionnaires Correlations	26 families, mean age mother=34, father=36.	Mean age=5.12 (range 3-7, 73.1% male)	Sense of coherence (SOC; Orientation to Life Questionnaire)	Ways of Coping Questionnaire	Accepting responsibility negatively correlates with SOC. Use of distancing, self-controlling and seeking support positively correlated with SOC	Fair

Milshtein et al. (2010)  Israel	Predictors of parental resolution of diagnosis	Cross-sectional Questionnaires; semi-structured interview coded for resolution; ANOVAs	61 families N=121, mean age mother=39.05 father=41.93.	Mean age male=7.9, female=8.3, (range 2-17, (55.7% male)	Reaction to Diagnosis Interview (RDI)	Parental broad autism phenotype (BAP) Family Impact Questionnaire (FIQ)	Resolution status not associated with child characteristics, duration of time since diagnosis, parent BAP. Resolution negatively associated with impact on social lives, negative feelings about parenting and negative impact on marriage (only in mothers).	Good
White (2009)  USA	Relationships between religiosity, parental well-being and acceptance	Cross-sectional Questionnaires Correlations	177 parents, (87% mothers) mean age=39.	Mean age=9 (range 2-31, 89% male)	Autism Acceptance Scale Psychological General Well-being Index (PGWBI)	Religious beliefs Religious practice Stressors of Parents of Children with Autism Checklist	Correlation between stress and well-being higher for those categorised as low religiosity. Also associated with acceptance	Poor
<b>Positive Growth</b>								
Phelps et al. (2009)  USA	Relationships between stress, enrichment and pt growth	Cross-sectional Questionnaires Correlations, multiple regression	80 parents (97.5% mothers)	Mean age=10.75 (range 3-35)	Posttraumatic Growth Inventory	Stress Enrichment (Effects of the Situation Questionnaire)	Enrichment predicts posttraumatic growth independently of child severity. Stress and enrichment not significantly negatively correlated – co-exist	Poor

Smith et al. (2008)  USA	Relationships between coping and maternal well-being	Cross-sectional Questionnaires Regression	352 mothers. Toddlers group N=151, mean age=36. Adolescents group N=201, mean age=44.74.	Toddlers: child age 18-34 months, 78% male. Adolescents: child age 10- 21 years, 74% male	Personal growth subscale from Scales of Psychological Wellbeing	Coping (Coping Orientations to Problems Experienced - COPE)	In toddlers: High levels of active coping, planning and positive reinterpretation and growth (problem- focused) predicted personal growth. Denial and behavioural disengagement (emotion-focused) predicted low personal growth. Similar for adolescents except denial not predictor. Some interaction effects	Fair
Tarakeshwar and Pargament (2001)  USA	Relationships between religious coping and perceptions of psychological and spiritual growth	Cross-sectional Questionnaires Regression	45 parents (95.6% mothers).	Mean age=10.29 (range 4-24, 80% male)	Stress-related growth Closeness to God Closeness to church Spiritual growth	Religious coping (RCOPE) Religious involvement Stress (autism specific)	Greater use of positive religious coping associated with better religious outcome and greater stress-related growth	Poor

All studies used self-report questionnaires (some completed through structured interview), and most were cross-sectional, although three papers included longitudinal data (two using the same sample). Results reported were typically correlations or regression analyses although some used statistical modelling. Included studies contained a wide range of outcome measures approximating to positive adjustment, which were organised into three categories: positive well-being (e.g. positive affect, life satisfaction, positive psychological well-being, self-esteem, self-efficacy, child-related enjoyment, optimism, sense of control); positive adaptation (e.g. family adaptation, sense of coherence, positive contributions, resolution of diagnosis, acceptance); and positive growth (e.g. personal growth, spiritual growth, post-traumatic growth). Some studies also assessed negative adjustment in parallel to positive adjustment, but these results are not reported in the current review. Qualitative responses, such as responses to open-ended questions, likewise are not reported.

#### *Quality of included studies*

Table 2 presents the ratings for each of the studies on the ten quality criteria, and total scores. Appendix A1 includes the full quality appraisal tool, with descriptors.

**Table 2: Methodological quality of included studies**

Paper	A. Appropriate study design	B. Sample selection adequately described	C. Description of inclusion and exclusion criteria	D. Adequate sample size	E. Sample Representative	F. Adequate description of demographic and clinical info of child and parent	G. IV and DV measures valid and reliable	H. Adequate description of data	I. Appropriate use of statistical analysis (inclusion of confounding variables)	J. Key results summarised	Total /20
Smith et al. (2011)	2	2	2	2	0	1	1	0	2	2	14
Ekas et al. (2010)	1	2	2	2	0	2	1	2	2	2	16
Ekas et al. (2009)	1	2	2	2	0	2	1	2	2	2	16
Samios et al. (2011)	1	2	2	1	1	2	1	2	2	2	16
Samios et al. (2009)	2	2	2	2	1	2	1	2	2	2	18
Samios et al. (2008)	2	2	2	2	1	2	1	2	2	2	18
Kuhn and Carter (2006)	1	2	1	2	0	2	1	1	2	2	14
Greeff and Van Der Walt (2010)	1	2	2	0	0	2	2	0	1	0	11
Kayfitz et al. (2010)	1	2	2	0	1	2	2	2	1	2	15

Pisula and Kossakowska (2010)	1	2	2	0	0	1	2	2	1	2	13
Milshtein et al. (2010)	1	2	2	1	1	2	2	2	2	2	17
White (2009)	1	1	1	2	0	0	1	0	1	2	9
Phelps et al. (2009)	1	2	0	2	0	0	2	0	1	1	9
Smith et al. (2008)	1	2	2	2	1	1	1	2	2	2	16
Tarakeshwar and Pargament (2001)	1	2	0	0	0	1	1	0	2	2	9



Sample sizes varied across the studies; nine included a sample of over 100 parents, and four included less than 50, which was likely to be insufficient for the number of variables analysed, although power calculations were not reported in any of the papers. Most studies highlighted limitations of poor representativeness, in that they primarily included Caucasian, higher income families, and two did not report any sample characteristics (Pisula and Kossakowska, 2010; Milshtein et al., 2010). All samples were recruited on a voluntary basis, leading to a self-selection bias. Studies incorporated a wide child age range, with some including children into adulthood, which would be expected to have an effect on parental adjustment (Smith et al., 2011; White, 2009; Phelps et al., 2009; Tarakeshwar and Pargament, 2001). Some studies did control for this statistically (Milshtein et al., 2010), or through inclusion criteria (Samios et al., 2008, 2009, 2011) or by including narrow age ranges (Pisula and Kossakowska, 2010; Smith et al., 2008).

Although stated as inclusion criteria for the sample, many studies did not independently validate the presentation of autism (seven did: Milshtein et al., 2010; Smith et al., 2011, 2008; Phelps et al., 2009; Samios et al., 2008, 2009, 2011). Only four studies controlled for autism symptom severity (Smith et al., 2011, 2008; Phelps et al., 2009; Milshtein et al., 2010), and although three others only included children with Asperger syndrome (Samios et al., 2008, 2009, 2011), most incorporated children across the whole autism spectrum. Some studies did not use research-validated measures (White, 2009; Tarakeshwar and Pargament, 2001), or used adapted versions of these (Ekas et al., 2009, 2010; Samios et al., 2008, 2009, 2011), potentially invalidating the established psychometric properties of the scales. Most

were cross-sectional studies that cannot offer conclusions about the direction of causality, even if predictive relationships are found through regression analyses. In addition, the predominant use of self-report measures may have inflated associations because of overlap in measures.

### **Narrative synthesis**

It was not possible to synthesise the data and findings from these papers into a meta-analysis, given the wide range of variables included, and the diversity in scales used to measure similar variables. A narrative exploration of key findings follows, structured by psychological predictors examined.

#### *Social support*

Smith et al. (2011) looked at three indicators of social support: social support network size, positive support (e.g. that those in a person's support network could be confided in, were respectful, provided care), and negative support (e.g. that those in a person's support network were critical, blaming or demanding). They found that high network size and low negative support predicted positive affect, but that there was no association with positive support. However, Ekas et al. (2010) found that the quality of three types of social support was associated with positive adjustment: family and friend support was associated with positive affect, and partner support was related to life satisfaction and psychological well-being. Greeff and Van Der Walt (2010) also found two general social support measures to be predictors of positive outcome, in terms of family adaptation. However, this study was rated as methodologically poor, due to the inadequate sample, and insufficiently described analysis.

### *Positive appraisal*

Psychological predictors in the category of positive appraisal included optimism, benefit finding, and stress enrichment. Ekas et al. (2010) identified an association between optimism and family social support, which was related to outcomes of positive affect, life satisfaction and psychological well-being. Ekas et al. (2009) found optimism had a strong relationship with higher religious beliefs, but not religious activities or spirituality.

Samios and colleagues (2009, 2011) developed the Benefit Finding Scale for Parents with a Child with Asperger Syndrome (BFS-PCAS). The BFS-PCAS consists of a global benefit finding factor, and six subscales (New Possibilities, Growth in Character, Appreciation, Spiritual Growth, Positive Effects of the Child, and Greater Understanding). They found that global benefit finding predicted positive affect, and the 'Positive effects of the child' subscale predicted life satisfaction in parents (Samios et al., 2009). However, further analysis of data from parent dyads highlighted that benefit finding was correlated between partners, and that global benefit finding ceased to be a significant predictor of positive affect independent of the partner's shared variance (Samios et al., 2011). They attributed this finding to the influence of sense making (see below *Parental cognitions*).

Phelps et al. (2009) researched stress enrichment using the Effects of the Situation Questionnaire (Yatchmenoff et al., 1998). Parents were asked to rate situations as to how much they made their life better, as well as how much stress they caused. They

found that stress and enrichment were not significantly correlated and seemed to co-exist, and that enrichment predicted positive adjustment in the form of post-traumatic growth, independently of child autism severity. However, this study was rated as methodologically flawed across a range of factors (Table 2). In contrast, Kayfitz et al. (2010) found a relationship between a related measure of benefit finding, the Positive Contributions Survey (Behr et al., 1992), and stress. They found that higher reporting of positive experiences was related to lower levels of parenting distress, although direction of causality cannot be determined.

### *Parental cognitions*

Sense making is conceptualised as the search for meaning, understanding or coherence in difficult experiences. Samios et al. (2008) developed the Sense Making Scale for Parents with a Child with Asperger Syndrome (SMS-PCAS), consisting of six factors: Spiritual perspective, Causal attributions, New perspective, Identification, Reframing and Luck/fate. They demonstrated that the 'Reframing' factor was related to positive affect and life satisfaction, although no others were found to be significant predictors. In parent dyads, as with benefit finding, sense making factors were correlated between partners, and an effect was found between the mother's 'Changed perspective' factor and the father's life satisfaction, highlighting the importance of including parent couples in research. Although these studies included a longitudinal element, no associations were found between baseline predictors and later adjustment. However, little change in level of positive well-being was found over the period assessed, perhaps due to the time already elapsed since diagnosis.

Kuhn and Carter (2006) examined the role of parental cognitive factors of maternal guilt, maternal agency and knowledge about autism in predicting maternal self-efficacy, an indicator of positive adjustment. They found maternal agency positively predicted, and maternal guilt negatively predicted self-efficacy in mothers with a child with autism. Interestingly, autism knowledge had no influence on feelings of self-efficacy, and the effects were found when controlling for a number of confounding factors, lending support to the distinct contribution of these cognitive constructs to self-efficacy.

#### *Religiosity and spirituality*

Three studies were included that looked at the role of religious beliefs and practices in predicting positive adjustment. In a measure of religiosity combining religious beliefs and practices, White (2009) reported small correlations between religiosity and autism acceptance, and religiosity and psychological well-being. However, these were not found to be statistically significant when error corrections were made. White also reported that stress had more of a negative impact on well-being in parents with low levels of religiosity compared to those with high religiosity, although this paper was rated as methodologically poor.

Ekas et al. (2009) looked at the role of religiosity as indicated separately by religious activities, beliefs and spirituality on a number of measures of positive adjustment. They found stronger religious beliefs predicted higher self-esteem and optimism, and spirituality predicted higher self-esteem, life satisfaction, positive affect,

psychological well-being and internal sense of control. In contrast, level of religious activities had a negative effect with a higher level of activities predicting lower self-esteem, psychological well-being, positive affect and internal sense of control.

Tarakeshwar and Pargament (2001) found no significant relationship between religious involvement and positive adjustment in terms of stress-related growth and spiritual growth in parents with a child with autism. However, they did find greater use of positive religious coping was associated with better religious outcome (e.g. feelings of closeness to God) and stress-related growth, although this study was rated as methodologically poor. Although these findings are contradictory, they highlight the importance of separating measures of religiosity into beliefs, coping and practices.

### *Coping strategies*

Three studies looked at the role of generic coping strategies in positive adjustment, although they used different measures. In a large sample study comparing mothers of toddlers and adolescents with autism, problem-focused coping strategies (active coping, planning and positive reinterpretation and growth) were found to predict positive adjustment in terms of personal growth in both mothers of toddlers and adolescents (Smith et al., 2008). An emotion-focused coping strategy, behavioural disengagement, predicted poorer positive adjustment in both groups of mothers, and the emotion-focused strategy of denial was only a significant predictor of poorer adjustment in mothers with toddlers.

Similarly, more active strategies of seeking support (positively) and accepting responsibility (negatively) were correlated with positive adjustment as indicated by sense of coherence (Pisula and Kossakowska, 2010). In contrast to Smith et al. (2008), use of distancing and self-controlling strategies (similar to behavioural disengagement) were positively correlated with sense of coherence (Pisula and Kossakowska, 2010).

Finally, passive appraisal was the only coping strategy that significantly predicted positive family adaptation in a study by Greeff and Van Der Walt (2010). Due to the inconsistency of findings and diversity of coping measures, it is difficult to make any conclusions from these.

## **Discussion**

### *Summary of key findings*

Inconsistencies in measuring predictors and outcomes, variable methodological quality and contradictory findings make summarising the literature difficult.

However, two of the strongest studies (Samios et al., 2008, 2011) point to the parental cognitive factor of sense making playing an important role in positive well-being, and accounting for some of the effects of other potential predictors such as benefit finding. This may overlap with the tentative finding that religious beliefs and spirituality are related to better adjustment, given that they can have a sense making role, as well as providing support and comfort. There was cautious support for the role of social support and particular coping styles, such as problem-focused and active coping, as helpful in positive adjustment, and this is supported by the

literature on negative adjustment (e.g. Benson and Karlof, 2009; Boyd, 2002; Benson, 2010).

Summarising the evidence is also problematic due to the conceptual overlap of some variables and their use as both predictors and outcome indices of positive adjustment (e.g. optimism, benefit finding). Research in this area needs to remain vigilant against concluding that one variable predicts a conceptually related other, without first establishing that they are representing separate constructs.

#### *Strengths of the review*

This is the first known review amalgamating research on predictors of positive adjustment in parents with a child with autism, rather than focusing on challenges and negative outcomes. By using exhaustive searching and broad inclusion criteria, it is hoped that all relevant research has been included, and that directions for future research can be developed.

#### *Limitations of the review*

This review was only able to include English language literature, and research that had undergone peer review, and will have missed any relevant unpublished dissertations. The review focused on measures of positive adjustment, although a number of the studies reported on negative outcomes in parallel, and analysis of these findings would enhance overall understanding of parental adjustment and coping.



### *Implications for research, clinical practice and policy*

In terms of clinical practice, clinicians should be mindful of parents' use of strength-based coping strategies, such as problem-focused and active coping, and cognitive approaches, and encourage the development of these to help promote positive adjustment. Given the importance of the role of sense making, incorporating a psychometrically validated tool, such as the Sense Making Scale (Samios et al. 2008), into clinical practice could aid assessment of coping and adjustment in parents with a child with autism, and identify potential avenues to promote adjustment. For example, post-diagnostic groups, peer befriending or psycho-educational courses could all be used to enhance parents' sense making and promote coping and social support. Exploring sense-making in a facilitated group setting may be particularly valuable in the area of autism where research on the causes of autism is ongoing and can be confusing for parents. However, any intervention should bear in mind Kuhn and Carter's (2006) finding that autism knowledge itself did not promote maternal self-efficacy, although maternal agency did, and look at how information about autism can be shared in a way that promotes parental agency, such as through group problem solving and case vignettes. Given the influence of partner adjustment on positive well-being, consideration should also be given to maximising the involvement of both parents in any interventions offered.

To develop this research area, consensus is needed about key variables that incorporate overlapping concepts, and are optimum indicators for positive adjustment, at a generic and autism-specific level. Measures need to be chosen which, when consistently used, enable direct comparison and merging of findings.

For example, Benson (2010) looked at coping dimensions used by parents with a child with autism, and found four distinct factors: engagement, distraction, disengagement and cognitive reframing. The review also highlighted the interactive effect of partners' adjustment on parents' well-being, and further research should include couples to account for this.

With further research establishing the evidence for risk and protective factors in positive adjustment in parents with a child with autism, policy recommendations can be made for providing interventions through schools, health services and relevant third sector organisations.

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## Appendix A1: Quality Criteria Tool

In general, a study scored 2 points if the principle was well addressed, 1 point if it was adequately addressed, and 0 if it was poorly addressed, not addressed or not reported.

	Criterion	Score
<b>A</b>	<b>Appropriate study design:</b> In researching predictors of positive adjustment, did the study use longitudinal data collection (2 points) or cross-sectional (1 point)?	
<b>B</b>	<b>Sample selection adequately described:</b> Were the sources and methods of sample selection reported transparently and the participants recruited fairly and openly?	
<b>C</b>	<b>Description of inclusion and exclusion criteria:</b> Were the eligibility criteria reported to demonstrate that a relevant and homogenous sample was recruited?	
<b>D</b>	<b>Adequate sample size:</b> Was the sample size acceptable given the use of multivariate analyses? Minimum sample of 50 participants, using rule of thumb of 10 or 15 cases per predictor variable. Score 2 if sample size equates to at least 15 cases per predictor variable, Score 1 if sample size equates to at least 10 cases per predictor variable, 0 if criteria not met. (based on guidance from Field et al., 2012)	
<b>E</b>	<b>Sample representative:</b> Were the participants representative of the demographic range of parents with a child with autism? For example, in terms of ethnicity, socio-economic status, marital status, parental employment and level of education	
<b>F</b>	<b>Adequate description of demographic and clinical info of child and parent:</b> Were the demographic information about the parents and the clinical information about the children reported transparently to allow consideration of potential confounding variables?	
<b>G</b>	<b>IV and DV measures valid and reliable:</b> Were all independent and dependent variables measured objectively by research-validated scales, with valid and reliable psychometric properties?	
<b>H</b>	<b>Adequate description of data:</b> Were the descriptive data of all variables clearly and accurately presented (e.g. means, standard deviations and confidence intervals)?	
<b>I</b>	<b>Appropriate use of statistical analysis (inclusion of confounding variables):</b> Given the research question of researching predictors of positive adjustment, were appropriate statistical tests used, i.e. multiple regression? Where relevant, were confounding variables (e.g. length of time since diagnosis, severity of presentation) included in analyses, if they were not accounted for in inclusion criteria?	
<b>J</b>	<b>Key results summarised:</b> Were results of all planned analyses reported, whether results were significant or not significant, and their effect sizes?	



## Chapter 2: Bridging chapter

The preceding systematic review examined psychological predictors of positive adjustment in parents with a child with autism. Although a range of potential predictor variables have been examined, including social support, coping styles and religious beliefs, the results of the review were inconclusive due to the conceptual overlap of predictor variables, and inconsistent use of outcome indicators of positive adjustment. However, parental perceptions of their situation and themselves as parents were represented across a number of variables, such as sense making (Samios *et al.*, 2008); benefit finding (Samios *et al.*, 2009); and self-efficacy (Kuhn & Carter, 2006). These cognitive and perceptual factors are likely to be of relevance in understanding processes of adjustment.

There have been a small number of quantitative research studies on perceptions of parenting in parents with children with autism, which have mainly focused on self-efficacy. Coleman and Karraker (1997) identified self-efficacy to be an important influence on parenting behaviours, stress, coping and help seeking in a review of the general parenting literature. In terms of research with parents of children with autism, Hastings and Brown (2002) looked at the relationship between child behaviour problems, self-efficacy, and parental anxiety and depression. They found that self-efficacy mediated the effect of child behaviour problems on maternal anxiety and depression, but did not observe the same effect in fathers. As noted in the systematic review, Kuhn and Carter (2006) examined links between self-efficacy and related cognitions of agency, guilt and autism knowledge in mothers of children with autism. They found that self-efficacy was associated with higher levels of well-being,

higher feelings of agency, lower feelings of guilt, but was not related to autism knowledge.

Meirsschaut *et al.* (2010) sought to increase understanding of these processes by comparing perceptions of parenting and parental cognitions in parents who had both a typically developing child and a child with autism. Similar to Kuhn and Carter's study, they measured parental self-efficacy, guilt, agency and parenting stress and depression. They found that mothers reported lower self-efficacy in relation to parenting their autistic child compared to their typically developing child. However, this was related to higher feelings of stress and depression towards parenting both their children, suggesting that reduced self-efficacy relating to parenting the child with autism did have a wider impact.

Qualitative research with parents with a child with autism can contribute to a greater understanding of perceptions of parenting and processes of adjustment by examining these at an individual level. There has been some qualitative research looking at experiences of parenting a child with autism, particularly relating to the impact on the family, coping and adjustment.

Hutton and Caron (2005) interviewed parents of children with autism on their experiences of diagnosis, interventions and the impact of autism on the family. They reported a content analysis of replies to the questions asked. They described that parents commonly experienced feelings of stress about their child and frustration with services, but did not explicitly examine perceptions of parenting.

Corman (2009) deliberately sought to redress the emphasis in the literature on stresses and challenges of parenting a child with autism by focusing explicitly on positive experiences of care giving. Positives discussed by parents in interviews included observing their child develop, seeing joy in their child, and relief at receiving a diagnosis. Corman noted that finding positives in their experiences seemed to interact with parents' stress-coping processes, supporting the importance of understanding the role of parenting perceptions in dealing with stress.

Meirsschaut *et al.* (2010) reported on a qualitative addition to their quantitative study described above, by including a question on the impact of the child with autism on their family life. Common themes reported were 'it affects our whole life', a lack of understanding from many aspects of their social environment, and particular coping strategies used in response to these difficulties. Marshall and Long (2010) also looked at coping, examining the coping processes revealed in the content and structure of mother's stories about their child with autism. They suggested that mothers coped by making meaning about their experiences, as well as describing particular cognitive and behavioural coping strategies used.

Some researchers have used phenomenological approaches to qualitative research in order to understand the broader experience of parenting a child with autism, and uncover core common elements. Cashin (2004) applied a psychoanalytic structure to his analysis of the experience of parenting a child with autism. From his research, he argued that the parent was affected by the experience in ways that mimic autism,

through the themes of less spontaneity, less social contact and less things (i.e. material possessions). He likened the experience of parenting a child with autism to the parent being pulled into a vortex.

Similarly, in a hermeneutic phenomenological study by Woodgate *et al.* (2008), the essence 'living in a world of our own' captured the parents' experiences of feelings of isolation. This overall 'essence' was supported by the three themes of: vigilant parenting (the requirement to be always watching and protecting the child), sustaining the self and family (through helpful ways of coping), and fighting all the way (to access and get benefit from services).

Altiere and von Kluge (2009) explored the struggles and successes of parenting a child with autism with 26 couples. They identified five themes that emerged through their analysis on the challenges encountered: Development (noticing differences or delays in the child's development), Questioning (being unsure or confused about the child's behaviour), Devastation (at the diagnosis), Solutions (of seeking knowledge and interventions), and Growth (benefits recognised as a result of the experience).

The qualitative research described above all took place in North America, with the exception of Cashin (2004), which originated in Australia, and there has been limited research in the UK with parents about their experiences of life with autism. Ryan and Runswick-Cole (2009) conducted a study relating to perceptions of parenting, but this was limited to specifically examining parents' experiences of advocacy for their child with autism, and how this might translate into activism. Another UK based study, by Midence and O'Neill (1999), used grounded theory to explore parents'

experiences of diagnosis of their child with autism. Themes identified included parents' difficulties in understanding their child's behaviours, and a sense of relief following the correct diagnosis. This was described as a pilot study (n=4) on one particular aspect of the parenting experience, but it did begin to explore the impact of the experience on parents' sense of self.

The present study aimed to explore the experience of parenting a child with autism in a UK context, and uncover core common elements particularly relating to parents' perceptions of their own parenting roles, resources and abilities. Interpretative Phenomenological Analysis (IPA) (Smith, 1996) was chosen to most appropriately address this research question. There was no known research that had used IPA with this group of parents, although it had been used with young people with autism (Huws & Jones, 2008) and with siblings of children with autism (Petalas *et al.*, 2009). A deeper understanding of the self-perceptions of parents of children with autism will be useful to clinicians and services seeking to engage and work with these parents, particularly when embarking on 'parenting work'.

## **Thesis Aims**

The present study aimed to explore the experience of parenting a child with autism in a UK context, and uncover core common elements particularly relating to parents' perceptions of their own parenting roles, resources and abilities.

Key question: How do parents experience and make sense of their capacity and ability to parent their child with autism?

## **Chapter 3: Methodology**

### **Design**

The present research used the qualitative methodology of Interpretative Phenomenological Analysis (IPA) (Smith, 1996), and employed semi-structured interviews for data collection.

Qualitative methodology was most appropriate for addressing a research question exploring the idiographic experience of members of a particular group. Barbour (2000) argued that qualitative research can help to expose the mechanisms involved in particular phenomena by exploring the explanations and accounts of relevant individuals. This research was concerned with uncovering the richness and detail of the individual's experience of being a parent of a child with autism and the meanings given to it.

Interpretative Phenomenological Analysis (IPA), first conceptualised by Smith (1996), is a method of qualitative research that has become widely used in health and clinical psychology. Its appeal is that it combines a method of exploring the idiographic experiences of a group of people of interest, with a rigorous and systematic method of analysis. IPA views the participant as a cognitive, linguistic, affective and physical being, and assumes that there is a connection between what a person feels, thinks, says and does. At the same time, there is a recognition that this is not always transparent or straightforward, and the researcher has to interpret people's thoughts and affect from what they say (Smith & Osborn, 2008).

The theoretical background of IPA draws on three key concepts: phenomenology, hermeneutics and idiography (Smith *et al.*, 2009). The phenomenology aspect of IPA is concerned with the study of 'lived experience', that we can only come to understand something through speaking to those who have personally experienced it. Hermeneutics is the theory of interpretation and meaning, and in IPA concerns both how the participant comes to make sense of and give meaning to his or her own experience, and how the researcher interprets the participant doing this (called the 'double hermeneutic': Smith & Osborn, 2008). IPA acknowledges that all interactions, including research, take place within a social and cultural context, and emphasises transparency of the role of the researcher in this process, rather than trying to assert that it is possible to be truly objective. Therefore IPA recognises that the interpretation is a product of the data and the researcher, and is therefore one way of making sense of and understanding a phenomenon. Finally, idiography is concerned with the particular, and IPA argues that in order to uncover psychological phenomena in sufficient depth and detail, we need to look at individual instances of lived experience, which are not accessible through quantitative methods. Smith *et al.* (2009) argue that only by exploring phenomena in this way can we do justice to the complexity of human psychology itself.

IPA was chosen for the present study to enable a deep exploration of the research question: 'How do parents of children with autism experience and make sense of their parenting capacity and ability?' It was also selected because of its assumptions in focusing on affect and cognition, and the explicit stance it takes on the role of the



researcher in interpretation, fitting with the principal researcher's background in clinical psychology.

Alternative qualitative methods considered included discourse analysis (Potter & Wetherell, 1987) and grounded theory (Glaser & Strauss, 1967). Discourse analysis aims to uncover the construction of meaning through language used in social relationships and interactions, particularly in relation to the assertion of social and political identities. The underlying philosophical assumption of discourse analysis is that identities and accounts are created through language, whereas IPA assumes that people's accounts directly represent the phenomenon of interest, and their perceptions and cognitions about it (Starks & Trinidad, 2007). As the research question of interest was about people's perceptions and thoughts rather than language, discourse analysis was deemed to be unsuitable.

Grounded theory is more similar to IPA, in that it aims to explore the meaning of a phenomenon to gain richer understanding and insight, using participants' accounts and reflections of an experience. However, it makes more ambitious claims to develop a theory generalisable to a broader population, through a process of hypothesis testing and theoretical saturation (Dall'os & Vetere, 2005). The present research was more concerned with connecting emerging themes to existing literature on parents' perceptions than developing an explanatory theory, so IPA was chosen over grounded theory.

## **Research context**

Reid *et al.* (2005) argue that it is important for an IPA study to take into account and discuss the context in which the data is gathered. This includes the principal researcher's background and the setting from which the participants were recruited.

The principal researcher was thirty year old, white, English woman, who had lived in Scotland for twelve years. She was married and had no children herself, although became pregnant during the course of the research. She was a trainee clinical psychologist aligned in child and family services, and had worked with children and families for a number of years prior to doctoral training, including with parents in group parenting programmes. Her interest in autism began when she worked as a behavioural therapist with a young child with autism on a home intervention programme during her undergraduate psychology degree. She became aware of the challenges and stresses involved in parenting a child with autism, and wondered how families who did not have access to financial resources to enable them to run home programmes coped. More recently, she was involved in setting up a charity that worked with families with a child with autism, helping them to learn daily living skills, and she was on the board of directors of this organisation. The research participants were recruited through this organisation. She also worked with families with children with autism through the course of her clinical training, particularly in a specialist placement in a child learning disability service. Her clinical training was predominantly in cognitive-behavioural approaches. She was interested in how the experience of being a parent of a child with a challenging condition such as autism

impacted on the parent's sense of self, and how this occurred in the context of positive adjustment and coping.

### **Participants**

A purposive sampling method was used to recruit a homogenous sample that shared the experience of being a parent of a child with autism. Inclusion criteria were that participants were the parent and main caregiver of a child with a diagnosis of autism (including Asperger syndrome), and that their child had been diagnosed for over a year, in order that they were able to reflect on their experiences.

Smith *et al.* (2009) advocate the use of small sample sizes for IPA in order to engage deeply with rich data at an idiographic level. They suggest including between four and ten participants in research for professional doctorates. In total, nine participants were interviewed for this research, although the first interview (P01) was a pilot and was not included in the final analysis. Therefore the final sample consisted of eight parents, six mothers and two fathers. The age range of the parents was 37 to 52 years old, and the age range of their children was 4 to 9 years old.

Table 3 describes the participants and their child or children, with corresponding participant numbers and child pseudonyms. One parent (P07) had two children with autism. In two families (P02 and P04), the child with autism had a twin who was not autistic.

**Table 3: Participant information and pseudonyms**

Participant	Parent	Child with autism	Ethnicity	Siblings	Marital status	School
P02	Father	Rachel	White British	Alfie (twin)	Separated	Special needs
P03	Mother	Connor	White British	Adele	Married	Mainstream
P04	Mother	Gillian	White British	Helen (twin) Graham Lianne	Long term partner	Nursery
P05	Mother	Freddy	Asian	Bobbie Pinkie	Married	Special language class
P06	Mother	Euan	White British	Emma	Married	Special needs
P07	Mother	Adam Michael	White British	Gemma	Married	Language unit Language unit
P08	Father	Charlie	White British	None	Separated	Mainstream
P09	Mother	Tim	White British	Eleanor	Married	Language unit

### Recruitment

The participants in the study were all recruited through the mailing list of the voluntary sector service that the researcher was on the Board of. The charity operated a service for families with a child with autism aged 3 to 12 years old in an area of South East Scotland. The service had been running for about two years at the recruitment phase of the present research, and the mailing list included families who had received an intervention from the service, as well as those who were on the waiting list. Families typically contacted the service through self-initiation, or by referral from other agencies such as the NHS diagnostic service, education or social services. Data collected from the service about socio-economic status showed that families known to the service came from the full range of socio-economic

backgrounds, but with an over-representation of those from areas of least deprivation, as was the profile for the area in general.

Information about the research was publicised through the service mailing list by email, which had approximately 250 members, mainly parents as well as interested professionals. This initial invitation contained a brief outline of the research aims and what it would involve, along with inclusion criteria (see Appendix 1). A research information sheet giving further detail was attached to the email (see Appendix 2), containing the following information:

- The purpose of the research
- What the research would involve i.e. a single interview at a venue of their convenience
- The voluntary nature of involvement, and that they were free to withdraw at any time.
- That the interview would be audio-recorded and all data related to the participant would be kept securely and confidentially.
- The intention to disseminate the research, and that all data would be anonymised and any identifiable information removed
- The potential benefits and disadvantages to being involved
- Contact details for the researcher and supervisors if further information was required

Parents who were interested in participating were invited to contact the researcher by email or telephone.

Seventeen parents emailed the researcher expressing interest in the research. The researcher replied to explain the practicalities of involvement and identify possible dates for interviews, and attached the research information sheet again, encouraging people to read it if they had not already done so. Nine people confirmed they were willing to participate, and could attend an interview during the available period of data collection. Interviews took place during November and December 2011, and were arranged by telephone, allowing the interviewee to be a little more familiar with the researcher before the first meeting, and facilitating any further questions.

### **Ethical issues**

The research was carried out in adherence to ethical principles as stipulated by the British Psychological Society Code of Human Research Ethics (BPS, 2010). Ethical issues particularly pertinent to qualitative research were considered with guidance from Smith *et al.* (2009) and Houghton *et al.* (2010). The project received approval from the University of Edinburgh Doctorate in Clinical Psychology Programme Research Ethics Panel. The main ethical issues of relevance to this project were avoidance of harm, informed consent, confidentiality and conflict of interests.

#### *Avoidance of harm*

Although the research was not expected to cause harm to participants, it was considered that there was potential for mild psychological distress when discussing their experiences of parenting a child with autism. This possibility was highlighted to prospective participants in the research information sheet (see Appendix 2). If

participants became distressed during the course of the interview, the researcher, using her clinical skills and experience, managed this sensitively. A list of appropriate support agencies was given to participants who requested further support (see Appendix 3).

### *Informed consent*

Houghton *et al.* (2010) discuss the importance of ‘informed process consent’ in qualitative research, through revisiting the issue of consent at various stages of the research process, given that the experience of being interviewed might be unpredictable. In the present study, the information sheet, which was provided to participants before the interview, contained information about the research, what it would involve, including any potential risks and proposed methods of dissemination. This information was also reiterated at the outset of the interview before participants were asked to sign a consent form (Appendix 4). Participants were reminded of their right to withdraw at any time, and if they expressed any form of distress during the interview, their consent to continue was sought again. The voluntary nature of their involvement in the research was emphasised throughout, and no payments or other incentives were given for participation. A brief findings report was produced and disseminated to all participants at the end of the research to give acknowledgment and thanks for their involvement (see Appendix 11).

### *Conflict of interests*

In terms of potential conflict of interests, as mentioned, the researcher was on the board of directors of the voluntary sector service that the participants were recruited

from. However, she had no direct role in service delivery and was not known to service users. She was transparent about her dual roles as postgraduate researcher and charity board member in all communication with participants. It was emphasised in the information sheet and at the start of the interview that the research was independent of the service and that participation and data would not be shared with service staff. It was stated that a decision not to participate would not impact, positively or negatively, on the service received from the organisation.

### *Confidentiality*

In terms of confidentiality, it was made clear from the outset what information would be kept about the participants, and that the interview would be audio-recorded. Participants were reassured that data would be stored securely and that demographic and identifiable information would be kept separate from audio recordings and transcriptions.

Once interviewed, participants were assigned numbers and all names in the transcripts were changed, including those of the index child, partners, family members and professionals. Names of local services were also changed (e.g. to Service A) and were used consistently between transcripts. Names of schools and geographical areas were changed or removed and replaced with '[identifier removed]'.



The limits of confidentiality were stated, in that information could be passed on to third parties only if the researcher was concerned about risks to the participant or their child, but that this would be discussed with the participant if it arose.

### **Data Collection**

Interviews were chosen as the method of data collection most suitable for addressing the research question using IPA. According to Smith *et al.* (2009), interviews allow rapport to be developed with participants, invite them to offer a rich, in-depth and personal account of their experiences, and facilitate them to reflect on their thoughts and feelings about them. Focus groups were thought to be unlikely to give space needed for personal, detailed reflection on individual experiences, and would add a layer of complexity to the data transcription and analysis.

Semi-structured rather than fully structured interviews were selected to permit the exploration of experiences and feelings of significance to the interviewee. This was balanced with the desire to direct them towards areas of pertinence to the research question, and have some degree of consistency between interviews, which might have been more difficult with an unstructured interview. An interview schedule was constructed using guidance from Smith *et al.* (2009) and Dallos and Vetere (2005). This was revised through discussion with the academic supervisor, and further following the pilot interview.

#### *Pilot interview*

The first interview conducted was a pilot for the researcher to practice her interview technique and to assess and develop the interview schedule (Appendix 5). The pilot interview began by asking about what it had been like for the participant being a parent of a child with autism. Following the pilot, it was felt that this question was quite abstract, making it awkward and difficult to answer, particularly as an opening question. Therefore, two questions were added at the beginning that asked about specific, familiar and concrete things, to describe their child and their experience of diagnosis, in order to help the participants begin to talk. A closing question was also included following the pilot, asking parents what they had gained from their experience, as this theme had arisen in the course of the interview, and was felt to be a positive way to end what might be an emotional discussion. Changes made to the content and structure of the interview schedule were deemed significant enough that the pilot interview was not included in the final analysis.

### *Interview schedule*

The interview schedule consisted of seven open questions (with supplementary questions acting as prompts) relating to the research question (see appendix 6 for full schedule):

1. Tell me about your child, what are they like?
2. What can you remember about when your child was first assessed and diagnosed?
  - What was your reaction? How did that make you feel? How did that affect you as a parent?

3. Can you tell me what it has been like for you being a parent of a child with autism?
  - How does it impact on daily life
  - Family (other children and other parent/ extended family/ key relationships)
  - What is the most challenging thing about being \_\_\_\_\_'s parent?
  - What's the best thing about it?
4. What do you see as important to your role as \_\_\_\_\_'s parent?
  - E.g. practically, emotionally, socially
  - How do you see yourself as a parent? How has this changed over time?
5. What do you think impacts on/ affects **how you are** as a parent?
  - E.g. can you think of experiences that you have had that have influenced how you parent
6. What do you think impacts on **how you feel** as a parent?
  - E.g. can you think about experiences that you have had that have given you confidence/ made you doubt your parenting
7. What's the most important thing you have got out of/ learnt from being \_\_\_\_\_'s parent?

The questions followed the verbal and informal administration of the demographic information questionnaire (Appendix 7) in order to settle the participant into the interview by asking about factual information and orientating the person to the topic of interest. The interview questions were administered flexibly in response to what

the participant talked about. Additional probes were also used where necessary, such as ‘tell me more about that’, ‘how did you feel?’ and ‘what were you thinking?’ The interview ended by enquiring if there was anything that had not been asked that they felt was important to their experience, or if they had any questions for the researcher. There was a short debrief, checking how the interview experience was for the participant, and explaining what would happen next in terms of contact from the researcher.

All the interviews were arranged to take place at a location of the participant’s choice. Most took place at the interviewee’s home (n=7), and one took place at a participant’s workplace at the end of their working day. The interviews were expected to last about an hour. In reality, the shortest one was 56 minutes, and the longest was 1 hour 47 minutes.

#### *Data management and transcription*

Interviews were audio-recorded using a digital recording device. Files were downloaded onto a computer as soon as possible after the interview and deleted from the device before the next interview. All interviews were transcribed verbatim by the researcher, enabling her to become more familiar with the data. Features of speech such as laughs, gasps and crying were also noted. A discernable pause was denoted by [5], with the number indicating length in seconds. Following transcription all names were changed and identifiable information removed.

## **Data analysis**

IPA has a flexible approach to data analysis, but focuses on how participants attempt to make sense of their experiences. At all times there is the awareness of the double hermeneutic, that the researcher is endeavouring to make sense of the participant making sense of their experiences (Smith & Osborn, 2008). Guidance on the analysis process was given by Smith *et al.* (2009), and through attending an analysis workshop facilitated by Paul Flowers, co-author of Smith *et al.* (2009).

The data were analysed after all interviews were transcribed. This was so that the analysis did not influence the researcher's approach to the interviews or questions asked. Transcripts were printed with line and page numbers and large margins on both sides of the text. The researcher considered using a qualitative research software programme (Nvivo) to organise the data and assist with analysis. Bergin (2011) advocates that software use can help with consistency in the coding process, although he does acknowledge a number of challenges. On trying out the software, the researcher felt that using a paper and pen technique would give her more control over the analysis process. She felt the software created too much distance from the data, and influenced the coding towards a more descriptive, rather than exploratory, idiographic and interpretative level in keeping with IPA.

### *Process of data analysis*

To maintain an idiographic focus, each interview was analysed in turn, starting with the last interview and working backwards in order. It was felt that the researcher's interview technique developed throughout the course of data collection and she

became more confident with the participants. Therefore, the final interview was thought to have some of the richest and engaging data, as well as being most recent in the mind of the researcher.

To begin with, the researcher read the transcript while listening to the audio-recording of the interview, in order to be fully immersed in the data, and to develop a sense of the interview structure and the individual. Minimal notes were made at this time of initial observations and impressions on listening to the interview again.

Next, notes and comments were made in the right hand column on the semantic content and use of language in the interview, line by line, section by section. These focused on what was important to the participant, including relationships, processes, places, events, values and principles (Smith *et al.*, 2009), and the meaning of these for the person. From this, conceptual and interpretative notes were made as they arose.

The next stage was to examine these initial notes and code them into emergent 'sub-themes' that expressed the essence of the important aspects of the transcript. The question was asked 'what does this page/ section say about this person's perception of himself or herself as a parent?' This was acknowledged to be a construction of the participant and the analyst. The themes were noted in the left hand column (see Appendix 8 for an example).

The sub-themes for the first interview were then collated and rearranged into semantic and conceptual clusters. This was done electronically as well as being cut up by hand and moved around on a large table. The grouped clusters were then named to try to capture the essence of the data in those sub-themes. In the first interview analysed, 21 sub-themes were reduced to three over-arching conceptual themes. Interview extracts were then pulled out to represent these themes. Then the process began again with the next interview, holding in mind themes from the previous interview, whilst being open to new themes emerging. In practice, themes from subsequent interviews were organised into these three initial over-arching themes, and further sub-themes were coded into these. Therefore each interview had its own file of sub-themes within the three over-arching themes, with supporting extracts.

On completion of analysing each interview individually, all sub-themes were listed in one table, and combined where there was conceptual overlap. Incidences of themes in interviews were tabulated, and those that were present in only a single interview were excluded. Using mind mapping, concepts were organised spatially, so links could be visualised and the relationships between them plotted. Through this analytical process, the three originally identified over-arching themes were transposed into five super-ordinate themes, and 11 sub-themes. Interview codes and theme summaries were then revisited to check that these themes accurately captured the interview data and the incidence of themes in each interview was recorded in a table (see Table 4). Finally, extracts from all the interviews representing each super-ordinate theme were collated in five respective files.

The journey of analysis reflected the iterative process of the hermeneutic circle (Smith *et al.*, 2009) of moving between the particular idiographic detail of the transcripts, to the overarching and recurrent themes, in the context of the researcher's perception and interpretation.

### **Reflexive diary**

The importance of reflexivity in research is emphasised in IPA, and refers to the awareness of the role of the researcher's values and presuppositions in the collection, selection and interpretation of data. Shaw (2010) argues that it is necessary to embed a reflexive attitude within qualitative psychology because of the co-construction of meaning between the researcher and researched. The aim of reflexivity is not to objectively remove these values, but transparency aids the credibility of the analysis. Finlay (2002) defines reflexivity as a continuing, dynamic, and subjective process of self-awareness.

The researcher's reflexivity was accounted for in the present research through the use of a research diary at various stages of the research process (see Appendix 10 for an example). The diary was started during the initial phases of deciding on the research topic and question, and continued throughout the research journey, through analysis and report writing. Particular attention was taken to record the researcher's motivations and assumptions prior to the interviews, and reflect on salient themes after the interviews, with observation of the researcher's perspective in influencing



these. Post interview reflections were facilitated using the following questions adapted from Banister *et al.* (1994) and Dallos and Vetere (2005):

- How might the context of the interview have affected the process?
- What ideas were developed, suppressed and linked?
- Were there any inconsistencies or puzzling links, threats to safety and how were they resolved?
- Were there any larger discourses at work?

### **Validity in qualitative research**

It has been recognised that evidence from qualitative research in psychology should not be evaluated against the same criteria as quantitative methodology, and various guidelines have been developed to assist with this (Elliott *et al.*, 1999; Chenail, 2011; Spencer *et al.*, 2003; Yardley, 2008). The present research was audited against the four broad principles for assessing quality of qualitative research presented by Yardley (2008): sensitivity to context; commitment and rigour; transparency and coherence; impact and importance. These principles were also incorporated in a quality evaluation guide to IPA papers by Smith (2011).

#### *Sensitivity to context*

The principle of sensitivity to context was demonstrated through the use of the existing research and theoretical literature in developing the research question and method, and in relating to the analytical findings. The researcher was also mindful of socio-cultural context of the participants, given her clinical and voluntary work experience with families with a child with autism. This experience facilitated her in

her recruitment and engagement with research participants, and aided data collection through successful interviews. The nature of IPA in immersing the research in the participants' lived experience is a further demonstration of sensitivity to context, remaining close to the narrative in the analysis, and using verbatim quotes as illustration.

### *Commitment and rigour*

The principle of commitment and rigour is integral to IPA as a systematic and thorough method of data collection and analysis. To do IPA well requires considerable personal investment as well as an in-depth engagement with the research topic. In addition to reading, the researcher's knowledge and skills in IPA was developed through regular attendance at the monthly Scottish IPA Interest group during the research process and participation in the one-day workshop on IPA Analysis in March 2012, both facilitated by Paul Flowers. She also participated in two IPA internet discussion forums (international and Scottish) where IPA researchers posted comments, issues and research dilemmas (<http://groups.yahoo.com/group/ipanalysis/> and <http://uk.groups.yahoo.com/group/scottish-ipa-group/>).

### *Transparency and coherence*

Transparency and coherence were adhered to by keeping an electronic and paper trail of all stages of the research process, particularly during the analytic journey, which is available for independent audit. Methodology and analysis has been described in a transparent way, and in the results section, verbatim quotes used to illustrate themes

have been referenced through participant and line numbers. The extracts allow the reader to evaluate the researcher's interpretation of the individual's narrative to the theme. Appendix 8 contains an example of coding in a section of transcript, and Appendix 9 provides a table of extracts to evidence the presence of themes for one participant's interview. The researcher also kept a reflexive diary in order to demonstrate as far as possible transparency in presuppositions and attitudes. An extract from this can be found in Appendix 10. The description of the researcher's background earlier in this chapter also allows the reader to consider how this may have influenced the research process.

### *Impact and importance*

The principle of impact and importance was represented in the unique research question not yet addressed by the literature, and thought to be of clinical importance. The theoretical and practical implications of the research findings were explored in the discussion section. Findings were disseminated to participants in a brief report, and to professionals through presentations to the clinical and voluntary services that the researcher was working with. It was hoped that findings would be disseminated more widely through the publication of a journal article.

## **Chapter 4: Journal article**

This journal article was prepared in accordance with guidelines for the journal *Autism* (Appendix 12).

# **An interpretative phenomenological analysis of the experiences of autism and perceptions of parenting in parents with a child with autism.**

## **Abstract**

*Background:* Research has highlighted that parenting a child with autism can be challenging and stressful. However, there is less known about the parental perceptions of this experience and processes of adjustment.

*Method:* Semi-structured interviews were conducted with eight parents of children with autism on their experiences of being a parent, and their perceptions of influences on their sense of self. The data were analysed using interpretative phenomenological analysis (IPA).

*Results and conclusions:* Two inter-related themes that represented how the unique presentation of autism in the child related to the parenting experience were presented: ‘experiencing autism as hard to know’ and ‘experiencing autism as all-consuming and extreme’. These experiences were highlighted as important in impacting on the parent’s sense of self in terms of doubting one’s judgement and believing the task of parenting to be impossible. These insights will be useful to those seeking to engage and support families with a child with autism, and assist parents with coping and adjustment.

## *Keywords*

Autism, parents, perceptions, interpretative phenomenological analysis

## **Introduction**

Research has consistently suggested that parenting a child with autism has a greater impact on parental stress and mental health than parenting children with no known disabilities (e.g. Eisenhower et al., 2005; Hastings, 2008). Hassall and Rose (2005) emphasised the importance of the role of parental perceptions and cognitions in adaptation to the demands of caring for children with developmental disabilities, including parenting self-esteem or self-efficacy, parental attributions and parental locus of control. The role of parental perceptions in parents with a child with autism has been investigated quantitatively through the conceptualisation of variables such as sense making (Samios et al., 2008); benefit finding (Samios et al., 2009); and self-efficacy (Kuhn and Carter, 2006), although research so far has been limited.

Qualitative research can contribute to a greater understanding of the unique experiences of parenting children with autism and examine processes of adjustment through exploring parental perceptions.

There has been some qualitative research looking at experiences of parenting a child with autism, particularly relating to the impact on the family, coping and adjustment (e.g. Marshall and Long, 2010; Corman, 2009; Hutton and Carron, 2005). Some researchers have used phenomenological approaches to qualitative research in order to understand the broader experience of parenting a child with autism, and uncover core common elements (Cashin, 2004; Woodgate et al., 2008; Altieri and Von Kluge, 2009). However, there has been limited research in the UK with parents about their experiences of life with a child with autism. Midence and O'Neill (1999) used grounded theory to explore parents' experiences of the diagnosis of their child with

autism. Themes identified included parents' difficulties in understanding their child's behaviours, and a sense of relief following the correct diagnosis. This was described as a pilot study with a small sample focusing on one particular aspect of the parenting experience, but it did begin to explore the impact of the experience on parents' sense of self.

The present study aimed to explore the experience of parenting a child with autism, and uncover core common elements particularly relating to how this impacts on these parents' perceptions of themselves as parents. There was no known research that had used Interpretative Phenomenological Analysis (IPA) (Smith, 1996) with this group of parents before, and this method was chosen to most appropriately address this research question, using semi-structured interviews.

## **Method**

Interpretative Phenomenological Analysis (IPA) employs a systematic method of qualitative data collection and analysis to study the idiographic, in-depth experiences of a group of people of interest (Smith et al., 2009). It was particularly selected because of its focus on the importance of affect and cognition in experience, which was particularly relevant to this study of parental perceptions, as well as the explicit stance it takes on the role of the researcher in interpretation (Smith and Osborn, 2008).

### *Participants*

A purposive sampling method was used to recruit a homogenous sample that shared the experience of being a parent of a child with autism. Inclusion criteria were that participants were the parent and main caregiver of a child with a diagnosis of autism (including Asperger syndrome), and that their child had been diagnosed for over a year, in order that they were able to reflect on their experiences. In total, nine participants were interviewed for this research, although the first interview (P01) was a pilot and was not included in the final analysis. The final sample consisted of eight parents, six mothers and two fathers (denoted by P02 to P09). The age range of the parents was 37 to 52 years old, and the age range of their children was 4 to 9 years old.

### *Procedure*

The participants in the study were recruited through a voluntary sector service for families with a child with autism in an area of South East Scotland, UK. An invitation to participate in the research was sent by email to the service's mailing list (approximately 250 members). The invite explained the aims of the research, inclusion criteria and that it would involve a single interview that would be audio-recorded. Seventeen parents initially responded, and nine people confirmed they were willing to participate, and could attend an interview during the available period of data collection. The interviews were conducted during 2011 with the informed consent of the participants. Ethical approval for the research was granted by the host institution.



### *Data collection*

Each participant was interviewed once by the first author (a white female researcher and trainee clinical psychologist). All the interviews took place at a location of the participant's choice, mostly at their home or place of work. The interviews lasted for between 56 and 107 minutes, and there was no payment for participation.

An interview schedule with open-ended questions was prepared prior to the interviews. Topics included initial recognition and assessment of autism, daily experience of parenting, impact of autism on the family, influences on parenting approaches, influences on sense of confidence as a parents, and challenges and learning from the experience. The interview questions were administered flexibly in response to the participant. Additional probes were also used where necessary, such as 'tell me more about that', 'how did you feel?' and 'what were you thinking?' Participants were encouraged to talk freely about their own individual experiences.

Interviews were audio-recorded using a digital recording device. Interviews were transcribed verbatim, and, following transcription, all names were changed and identifiable information removed.

### *Data analysis*

Transcripts were analysed manually by the first author for recurrent themes using IPA (Smith et al., 2009). To maintain an idiographic focus, each transcript was analysed in turn. The first stage involved exploratory coding, commenting on and labelling the data at a line-by-line level. The second stage involved examining these

initial notes and coding them into emergent ‘sub-themes’ that expressed the essence of the important aspects of the transcript. On completion of analysing each interview individually, all sub-themes were examined and combined where there was conceptual overlap. Using mind mapping, concepts were organised spatially, so links could be visualised and the relationships between them plotted. Through this analytical process, recurrent over-arching themes and sub-themes were identified. Initial transcript codes were then revisited to check that these themes accurately captured the interview data. Extracts from every interview representing each over-arching theme were collated.

## **Results**

Through the analysis, a number of themes emerged relating to the experience of parenting a child with autism and how it impacted on parents’ sense of self. This article highlights two recurrent, inter-related themes that represented how the unique presentation of autism in the child related to this parenting experience: ‘experiencing autism as hard to know’ and ‘experiencing autism as all-consuming and extreme’. These themes will be discussed and illustrated by extracts chosen as representative of the participants’ experiences.

### *Experiencing autism as hard to know*

When discussing their experiences of having a child with autism, the theme of autism being hard to recognise and understand was evident throughout all interviews. It was often difficult for parents and others in contact with the child, to recognise and understand that something was not right with their child’s development:

“...as he was our first child, I didn’t know what ‘typical’ behaviour would be, so I thought he was typical until I knew otherwise. And when I say he was difficult, he wasn’t as co-operative as some other children might be, erm, and in between his second and third year, it was starting to be obvious that Tim was a bit different. It wasn’t obvious to me at the time, but with hindsight it was obvious.” (P09)

In some cases, parents attributed their child's behaviour to a cause other than autism, such as having a new baby or gender differences. Many parents struggled to get other people and services to recognise the difficulties and listen to their concerns.

Participants described frustration at professionals who were involved in their child’s life, such as nurseries, health visitors and doctors, not picking up on problems with the child’s behaviour or development:

“...like the health visitor and that, they didn’t even notice it, which, when I look back, is quite annoying, cos you’d think, that’s their job!” (P07)

“I could not get him in the system, cos they wouldn’t listen. None of them would listen.” (P06)

Participants reported that professionals would attribute the child’s presentation to other reasons, such as being premature (P04), having bilingual parents (P05), having poor muscle tone (P06), or even the mother’s post-natal depression (P09).

The experience of noticing that there was something wrong with their child’s development but not having this validated led to parents questioning themselves, worrying about whether they were bad parents for thinking that the child might have difficulties:

“And I was devastated by that, because it makes you question yourself, even though you’re 100 per cent sure in yourself, it makes you, because these people are, you know these people are dealing with children coming through the system all the time, you kind of, think they know, and you, sort of, question yourself, as to what you’re thinking. Are you right? Are you being paranoid? You know, and actually no, I wasn’t, I was right...” (P06)

Participants often reflected on how they had attributed their child's challenging behaviour to poor parenting skills, rather than considering that the child might have an underlying condition:

“... she said ‘look, it’s not your fault, it must be really difficult’, you know, and I thought ‘oh, it’s not my fault’, I never thought that before, and then I suddenly realised that I did think it was my fault, which I hadn’t realised until then.” (P03)

In three cases, parents described themselves as having post-natal depression, and they felt this to some degree explained why they had blamed themselves for their child's problems. The depression also seemed to compound the struggle with the child's behaviour, and vice versa, leading to a vicious cycle.

Participants reported that eventually obtaining a diagnosis of autism was helpful in increasing their knowledge and understanding about their child, and enabling access to services. They also spoke of how obtaining a diagnosis helped them by reducing the blame they felt for their child's problematic behaviour:

“I started trying to adapt to those strategies straight away, and that made..., it just helped me understand Connor a little bit more. Erm, and yeah, it was like this huge, ‘it’s not my fault, I didn’t...’, that I’m not doing something wrong.” (P03)

“But, the good thing was, I had a reason for why I didn’t understand why my kids did what they did. So I wasn’t self-doubting myself anymore.” (P07)

However, the experience of autism being hard to know continued to be conveyed in the interviews even after the condition was diagnosed. Participants discussed the challenges of having a child with autism and finding them difficult to understand, or know what they were thinking, because of their unusual behaviour:

“It’s really complicated with Euan, because you’re always trying to figure out what behaviour’s attributed to what, you know?” (P06)

“You can feel sometimes, and I feel this, I can feel like, ‘well, did she get anything out of that at all? Was that a complete waste of time? Did she even notice? Did she even, what did she think about it?’” (P02)

Many parents described the challenges of trying to communicate with a child who had impairments in social communication:

“And the thing is, you know, with some autistic children, with Charlie anyway in particular, you couldn’t communicate with him, you couldn’t talk with him, like you would another child, you know, you just couldn’t. It’s really frustrating, and so, the only way to communicate would be to maybe have a bit of rough and tumble, or play with him, go for walks or whatever, you know. And somehow, you know, make your connection...” (P08)

Communication and connection with the child was seen as an important part of being a parent for a number of participants and therefore challenges in this area were particularly problematic and, in this extract, caused the parent to doubt himself:

“He, he didn’t even answer to his name. I used to think, have I given the wrong name? Maybe he wants another name.” (P08)

One of the most powerful moments during the interview with this father was when he described the struggle and efforts he made over time, and the subsequent reward when this connection was finally made:

“I used to play this game with Charlie, when he was about two and a half, two and a half, three, and I used to lie on the couch, and I’d pull the cushions over us, so it was completely black, and go ‘Charlie, Charlie, it’s me, your father, talk to me, so I can find you’, [whispering] and he wouldn’t say anything, he just, but he seemed to enjoy the game, you know. He seemed to realise that something was happening, but he’d never answer me [laughs]. And I did this for about a year, and then one day, he went ‘Dad, Dad, I’m over here’ [laughs]. I just about fell off the couch, it was amazing. But I mean [2], you know, that’s something I’ve learnt is that, er, if you’re patient and persistent, that eventually, you know, you get there.” (P08)

The relationship between communication and confidence was also demonstrated throughout the interview with P02. This father talked about feeling guilty for not spending enough time with his daughter, or for not always doing the ‘right’ thing

with her, whereas he spoke confidently about his parenting relationship with his (non-affected) son, who he acknowledged was much easier to connect with and understand.

Finally, the experience of autism being hard to know emerged in how people in the wider world often did not recognise a child as having autism:

“I guess its because its invisible, I guess its because its an uncomfortable one, its not tolerated, I guess because it looks like bad behaviour. Tim’s also quite intelligent so it’s hard for people to believe that he’s also seriously disabled.” (P09)

This meant that parents often felt judged and criticised by those who were unaware of the child’s condition:

“The most challenging thing, the thing that I hate is when we’re out, like, say we go to Ikea or anything like that, and we’re sitting having something to eat, and Gill is loud and shouting about something, because she’s not in her familiar surroundings, and the way that the other people stare, that’s what I hate. Like that you’re just, you’re not giving her a row, and like, you know, that she’s a really badly behaved kid, that’s what I hate. And that’s wherever you go, you get that a lot.” (P04)

Many of the parents interviewed felt that they had confidence to deal with this now, but reflected on how difficult they had found it in the past, and the impact it had had on their self-belief as a parent.

### *Experiencing autism as all-consuming and extreme*

The second theme captured the participants’ experience of autism as being all-consuming, demanding and impacting on all aspects of family life. Across all interviews, parents discussed how extreme and relentless the condition could be, providing many challenges:

“It’s extremely tiring, and [2], well it’s actually chronically tiring, I think that’s a good description of it, it’s chronically tiring, there is no let-up from it, there is no

day that is any easier than another day, erm, in terms of his behaviour. Some days are more aggressive, erm, and obviously some days are more fun, but they're equally difficult to get through." (P09)

Parents often described how their children needed constant attention in order for them to manage their behaviour, and vigilance in public places was required in order to keep them safe:

"...if Rachel's there, you're always having to hold her hand, you're always having to watch her, you can't do, you know, it really restricts what you can do and it can turn something that should be fun into something that's a chore, you know." (P02)

Some parents conceptualised the difficulties in quite extreme ways:

"...We're slowly coming to terms with the, the day-to-day issues that that presents. In some sense it feels like a life sentence, it is actually a life sentence for me, and for Tim in particular." (P09)

The description of the challenges as a 'life sentence' in this extract conveys the pervasiveness as well as the permanence of the difficulties experienced, for both child and mother. Other participants described how the demands of autism had changed their lives, meaning that family life had to revolve around autism in order for the child and the parent to cope:

"They can have quite profound consequences at times, erm, and at times they can, erm, sort of, affect family life totally, and I would say that, most of what we do as a family, and how we've done it, has built around Connor's needs." (P03)

Parents also commented on the impact that autism had on the child's siblings.

"It was really hard, and Freddy, you know, like, was quite aggressive towards his younger sister Bobbie, she was a baby at that time, and, you know, I can't leave them even, you know, like, for a minute, even to go to the loo, or, you know, like, I have to be present with him all the time..." (P05)

Often, siblings were subject to the child's aggression or frustrations, and in two cases this had led to siblings living with other relatives for a period of time. P09 noted that

her younger daughter's development had been negatively affected through her copying her brother's aggressive behaviour and socially inappropriate comments.

In addition to the general effect on family life, some participants discussed the impact that autism had had on their relationship with their partner:

“I suppose that is the worst thing as well, is we're not a couple as such anymore, because we can't be, cos there's so much, the kids are so demanding.” (P07)

Two of the parents interviewed indicated that autism had been a factor in their relationship breakdown.

This characteristic of autism being all-consuming, extreme, demanding and challenging led to a sense that parenting children with autism was an impossible task; that despite all the efforts made, they and their child still struggled, and their parenting did not always achieve the outcomes they hoped for:

“Everything that was suggested to us we did, everything we read about or, you know, thought would help him, we did, erm, and while we've tried to make his life better, we obviously cannot make him not autistic, and so we all have to live with that, and that's incredibly difficult for all of us, particularly for Tim.” (P09)

Participants talked about the frustrations that, despite their consideration, vigilance, and the efforts that they made to minimise difficulties or help their child, challenges continued to come up, and difficulties were ongoing:

“I think when, when he's younger, you just, sort of, deal with it, but I'm finding now, as he's getting a bit older, and we're still dealing with it, but I think about more how long I've been dealing with it, and how it's not really much better, and is it always going to be like this?” (P06)

Some parents spoke of challenges in balancing what they thought the child needed, even though it might involve pushing the child out of their area of comfort and



distressing them further. There was often a sense that they could never win, or be able to do the right thing, which could result in them feeling quite helpless:

“I keep thinking I ought to give him, try and give him some more responsibility, but he’s so reluctant to take it, I tend not to give it to him, but he does need to start having some more responsibility. Erm, it’s sort of, that balance as to how much to support, and how much to just let him get on with it, which I don’t think I’ve got yet.” (P03)

For many parents, the continued challenges had an inevitable impact on their sense of self as a parent. However, to believe that the job of being a parent of a child with autism was impossible in some ways protected their sense of self, and helped them to stop striving to find the ‘right’ way:

“I used to think, maybe two or three years ago, I used to think, yes, I will find the key [laughs]. I will unlock the challenges, you know, I’ll find the formula, and I will be able to, ‘no, forget about it, you can’t do that’. And I learnt a lot actually, from watching [his worker], how she worked with him and so on, beginning to understand that a) it’s a very, very long process, and there’s no, there’s no real epiphanies with autistic children, or eureka moments, not really. Or if they do have an epiphany, it’s over a week, you know.” (P08)

Some parents recognised that there were limits to being a parent, and that everyone struggled with it. It was acknowledged that this was not only in relation to parenting a child with autism:

“...this realisation that, we’re all just muddling on, and that I think that for a long time, I very much had this image that everybody else seems to know what they’re doing, in this parenting lark, it’s only me that’s sort of, muddling along, wondering whether I’m doing the right thing or not, till I realised there wasn’t actually a right thing, there’s just what happens.” (P03)

## **Discussion**

In summary, this study used IPA to explore the experience of parenting a child with autism, and the impact of this experience on parental sense of self. The characteristics of autism being hard to know and understand, and being all-

consuming and extreme were highlighted as important in impacting on the parent's sense of self in terms of doubting one's judgement and having confidence.

The theme in this study of autism being hard to know and understand was similar to the theme of 'confusion' identified in the study by Midence and O'Neill (1999). They noted that confusion about the child's behaviour led parents to feel guilty and blame themselves for their child's problems. Altieri and Von Kluge (2009) also identified the theme of confusion about the child's presentation when parents began to question why their child was different. The link between communication impairments in autism and parenting confidence is also supported by research by Osborne and Reed (2010), who identified that perceptions of being able to communicate with their child were impaired in parents with a child with autism, and related to parenting stress. Although the present study does not compare parents with children with autism with other developmental disabilities, some of the characteristics of the experience of autism that differentiate it from other disabilities may account for why it is so difficult for parents to cope with. That autism is usually diagnosed much later than other developmental disabilities, and that it is so difficult to recognise and identify clearly had an impact on parents, leading them to doubt their own judgement. That it is often difficult for others to recognise was also relevant. Lasser and Corley (2008), in their qualitative study, question whether the variable visibility of disability accounts for the increased impact of autism on parents, because of the stress of experiencing as well as anticipating their child's challenging or unusual behaviour in public places, given that their disability is

hidden (compared to, for example, children with Down syndrome or a physical disability).

The theme in this study of autism being all-consuming and extreme was similar to findings from qualitative studies by Myers et al. (2009) and Woodgate et al. (2008). In coding the questionnaire responses to an open-ended question on the impact of autism, Myers et al. noted that the theme of stress arose in over 70 per cent of responses, and parents gave wide-ranging examples of aspects of their lives that the autism impacted on, as in the present study. In a Canadian qualitative study by Woodgate et al., the theme of 'vigilant parenting' represented the extremity of demands of autism on the parent, similar to the present study. The concept of sense making (Samios et al., 2008) has been proposed as being important in the process of coping with a child with autism. In this study, making sense of the extremities of the autism presentation, and conceptualising the job of parenting a child with autism as an impossible task may be helpful in protecting parents from a sense of helplessness or feelings of failure as a parent.

It is hoped that the findings from this study will be useful to those working with families with a child with autism in understanding how the experience of autism impacts on parents. For those involved with assessment and diagnostic services, it highlights the difficulty for parents in beginning the assessment process, as well as in communicating their concerns, when the condition is hard to recognise. For those involved in supporting families and providing interventions to parents, it provides a greater understanding of the impact of these unique challenges on parents' self-

confidence. Normalising the experience of autism being hard to know and understand, and being all-encompassing and extreme may help to reduce their impact on parents. Many parents also commented that greater awareness about autism in society, to compensate for its lack of visibility, would help people to be less critical and reduce the impact of this on parents.

This is the first known study that used IPA to explore experiences of parenting a child with autism, and has provided interesting insights into the experience of this unique condition, particularly in developing our understanding of self-perceptions of parenting. Although the main findings have been supported in the literature, there are some limitations to the study. The participants were a self-selected sample of parents who were in contact with a voluntary sector service, and, as with all phenomenological interview-based studies, the group were skewed to consist of those who wanted to bear witness to their experience, and were able to articulate and reflect on this. The interviews occurred only at one point in time, and relied on the participants' memory of their retrospective accounts, which may have been skewed by their current perceptions and experiences. However, the data collection and analysis were systematic and rigorous, the themes represented the perceptions of the parents who participated, and the research was audited against quality guidelines on IPA papers by Smith (2011). Further qualitative research taking a longitudinal approach would be useful in exploring changes in the experience of parenting a child with autism as a child develops, and the corresponding impact on self-perceptions, in order to understand and best support families experiencing these challenges.

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## **Chapter 5: Additional Results**

Five super-ordinate themes emerged through the narratives. These themes and their sub-themes are represented in Table 4, with their occurrence in each interview.



**Table 4: Super-ordinate and sub-themes for all participants**

*Believing in self as a parent with a child with autism*

Themes	Participants							
	P02	P03	P04	P05	P06	P07	P08	P09
<b>A: Experiencing autism as hard to know</b>								
▪ Hard for parent and others to recognise and understand	X	<b>X</b>	X	X	X	X	X	X
<b>B: Experiencing autism as all-consuming and extreme</b>								
▪ i) Autism impacting on everything	X	X	X	<b>X</b>	X	X	X	X
▪ ii) Parenting autism as an impossible task	X	<b>X</b>	X	X	X	X	X	X
<b>C: Diagnosis giving understanding and confidence</b>								
▪ i) Making changes and doing something	X	X	<b>X</b>	<b>X</b>	X	X	X	X
▪ ii) Reducing blame and building confidence	X	X	X	X	<b>X</b>	X	<b>X</b>	D
<b>D: Parenting in the eyes of others</b>								
▪ i) Criticism and judgement of child and parent	<b>X</b>	X	X	X	<b>X</b>	X	X	<b>X</b>
▪ ii) Recognition and evidence of parenting skills	X	X	<b>X</b>	<b>X</b>	X	X	X	D
<b>E: Dilemma of acceptance</b>								
▪ i) Acknowledging pain and loss	<b>X</b>			X	<b>X</b>	X		<b>X</b>
▪ ii) Oscillating between fear and hope for the future	X	X	X		X		<b>X</b>	<b>X</b>
▪ iii) Meanings of acceptance	X	X	<b>X</b>	X	X	<b>X</b>	X	X
▪ iv) Finding positives and discovering rewards	X	X	X	X	<b>X</b>	<b>X</b>	<b>X</b>	X

X = theme present in interview

**X** = important theme for this participant

D = divergent to theme

The first two themes, *experiencing autism as hard to know*, and *experiencing autism as all-consuming and extreme*, represented how the unique presentation of autism related to the experience of parenting and how it impacted on parents' sense of self. The third theme, *diagnosis giving understanding and confidence* related to how gaining a diagnosis enabled changes in the way the child was understood and how parents could respond, and to their confidence. The fourth theme, *parenting in the eyes of others*, described how parents felt that their parenting was positively recognised or negatively judged by other people, at a real and imagined level. The fifth theme, *dilemma of acceptance*, encompassed the positive and negative meanings parents gave to accepting the condition of autism, acknowledging loss and discovering rewards in the experience.

#### **A: Experiencing autism as hard to know**

- **Hard for parent and others to recognise and understand**

Parents spoke of the difficulties they had experienced because the condition of autism is hard to identify, recognise and diagnose, and this often had an impact on their sense of self as a parent. Even after diagnosis, they described challenges around the 'invisibility' of autism, in that children did not look like they have a disability or developmental condition, and so their behaviour could be misunderstood by their family and the wider society. They also talked about the challenges of connecting with and understanding their child in the context of autism. These experiences of autism had implications for the parent's sense of self and led to questions about themselves as parents both before and after the diagnosis was made. This theme was discussed in the journal article in the preceding chapter.

## **B: Experiencing autism as all-consuming and extreme**

The second super-ordinate theme captured the participants' experience of autism as being all-consuming, demanding and impacting on all aspects of family life. Across all interviews, parents discussed how extreme and relentless the condition could be, providing many challenges, with the child requiring constant and vigilant attention. This characteristic led to a sense that parenting autism was an impossible task; that despite all the efforts made, they and their child still struggled, and their parenting did not always achieve the outcomes they hoped for. This impacted on their sense of self as a parent. This theme was discussed in the journal article in the preceding chapter, where it was argued that the belief that the job of being an autistic parent was impossible in some ways protected parents from a sense of helplessness or feelings of failure as a parent.

Additional supporting extracts for the impact of autism on everything (as well as divergent examples) are presented below.

### **▪ Bi) Autism impacting on everything**

When discussing their daily experience of life with a child with autism, participants often conveyed how challenging it could be. For many of the participants, the child often displayed difficult behaviour, being non-compliant, having tantrums or being physically aggressive, which had an impact on their daily lives:

...because for Freddy it's really good to keep him busy, otherwise his behaviours at home is really, can be really challenging, so. I feel obliged to go out, although I'm more like a, a home person, I'm not like that. (l. 599 P05)

A common subject was the difficulties parents had experienced in supporting their child's development and helping them to learn new skills. Many parents felt that doing most things required more time, consideration, effort and patience than it did for their other children, or than might have been the case if their child had not been autistic:

He's learnt to, he has learnt to control lashing out much more, but he can reach the point sometimes where frustration gets so high that he lashes out. And he still, he's, when he's tired at least, he's so slow to process things, it's still, you know, give him one instruction at a time, and everyday things, things he's done every day for years, like get ready in the morning, and get dressed and brush your teeth and have your breakfast and things (l. 633 P03)

And then I feel all the time I have to, to structure social activities for him, you know, to, to, like, invite friends, and then, you know, like, you know, like, make it clear what is, what will be expected of him. (l. 1082 P05)

Some participants found one of the most challenging things was that their freedom was restricted, and they were unable to do things spontaneously, because of the organisation that was required, and their child's inability to cope with this:

Not being able just to walk out your door, not having the freedom you had before. Cos, even when I had Gemma, I could still put on her jacket and we could still go out and go for a walk, go to the park, go to Granny's house. I can't do that with my boys, and I hate that, I actually hate that with a passion. That's, that is the worse thing ever, cos I'm quite a free spirit. I don't like being stuck in the house, I like to be out and seeing people and doing stuff and, and I can't do that anymore. (l. 767 P07)

These challenges and restrictions inevitably had an impact on the parents, and many admitted that it was sometimes difficult to get the motivation or energy to spend time with them or do what the child demanded of them:

...it's difficult with Rachel, you know, I can't always feel like it's fun doing stuff with her. (l. 751 P02)

I feel like I'm almost mortally injured by his condition. In other words, I have to live to look after him, to look after Tim, I have to live to look after Tim, but that sometimes I would rather be dead. And that doesn't mean I'm suicidal, I know the difference, I have experience of suicidal thoughts earlier in my life, er, I know the difference of that, but what I

am saying is, in some sense, it would be easier for me to be dead than to live this life. Please bear in mind that Tim is mildly autistic, not severely autistic, and he is a young child, so it is a indication of how devastating it is to live with, because he suffers on a daily basis, and I suffer as a result, and my daughter suffers because her life is [2] massively, adversely affected by his condition. (l. 747 P09)

For P09, the demands of autism on her life have been damaging to such an extent that she finds that it challenges her very existence. She comments that even though her child is ‘mildly autistic’, they experience major difficulties that impact on all members of the family.

Parents often spoke of finding it hard to balance the needs of their other children, because their autistic child was so demanding. Both P02 and P06 talked about one of the benefits of having respite care was that they could spend time with their other child. They acknowledged that this could be hard for the siblings who also wanted for their attention, but was also distressing for parents to miss experiences with their other children:

...it can be hard, because you can miss out on things your other kids are doing, cos Gillian doesn't want to be part of it (l. 63 P04)

However, some parents acknowledged that the experience had had a positive impact on their other children, for example, making them more responsible and considerate:

I mean he's really grown up for his age, erm, and he's beginning, he's got a lot out of this, I think you know, without, you know, just sort of, subconsciously and that you know, and he's very responsible, always, if she runs off, he'll always be the first to run after her, and go out and grab her, you know...(l. 1031 P02)

In addition to the general effect on family life, some participants discussed the impact that autism had had on their relationship with their partner:

...it's had a huge impact on that. I guess I should say that, about our immediate family, our marriage nearly failed, very nearly failed. Erm, I guess, in 2009 during the period

that we were waiting for a diagnosis we had to go to counselling to prevent our marriage from totally disintegrating. I, of course, blamed my husband for preventing me from seeking help for Tim and he essentially found me very difficult to live with because I was depressed. Erm, so basically it brought the family to, the immediate family to it's knees. (l. 561 P09)

In these cases, the parents remained together. However, P02 indicated how his relationship had broken down since his daughter was diagnosed with autism:

This caused us a lot of problems in our relationship actually, stuff with Rachel and that. I'll be doing stuff with Alfie at times and my ex-partner used to say, 'why don't you do that with her as well?', and like well, it's difficult because I'm doing something with Rachel and she just wants to pick up these pieces, throw them or walk away with them, I can't do this with both of them. I'll take them both swimming, er, or do these things, but she used to, erm, go on at me. It just caused a lot of problems and friction in our relationship, you know. I suppose my ex-partner was upset because she could clearly see that I was, er, doing more things with my son, you know. (l. 329 P02)

P08's relationship with his son's mother also broke down for different reasons. He described concerns about his ex-partner's ability to cope with their son and look after him adequately, and understood this to be because she had autistic traits herself. This resulted in their separation, and him becoming the primary caregiver for his son.

Although acknowledging the challenges that they experienced, many parents throughout the interview worked hard to balance this with positive experiences in parenting their autistic child:

I mean there is times obviously that you've had it, because she's attacked you so much in one day, that you just want to cry, but, like I say, it's just the next day she'll do something and you think, 'that's, you're just great (l. 1071 P04)

### **C: Diagnosis giving understanding and confidence**

The third super-ordinate theme captured the participants' experiences of the positive consequences of having a diagnosis of autism for their child, in spite of all the challenges. Although recognising the condition and having it professionally

identified often took time (see theme A), participants described how having diagnosis helped them to make sense of their child's difficulties, understand them better, and make positive changes in how they responded to them in order to support them. For many parents, it also reduced the sense of blame they had been feeling about their child's problematic behaviour, and gave them more confidence in their parenting skills.

▪ **Ci) Making changes and doing something**

Parents often talked about how helpful it was when they were given an explanation for their child's difficulties, or were given a diagnosis, as it gave them understanding of what to do next:

...and he said, erm, 'now have you..., do you know anything about Asperger syndrome?' And I said no, but, you know, what should I read? And he recommended a book, and it was quite ironic but I just sort of flicked through this book, opened it at a description of a child, and it was like the author had just described my son, and I, sort of, read it through, I was like, 'that's him, okay'. But that made such a difference. I mean, it took another year and a half to get a diagnosis, but school straight away said, 'okay, it might not be, but certainly, it shows, it looks likely, so let's respond and let's work as if he has for now, until we hear otherwise, and put the sort of support in place that you'd put for a child with Asperger syndrome. (l. 93 P03)

Given their feelings of confusion and helplessness, it was important to participants to be doing something proactive to help their child. Most participants talked about one of the most helpful aspects of obtaining a diagnosis for their child was that it enabled them to access services and get appropriate help for their child from others:

Actually, when she was diagnosed, it made everything easier for us because she could be, we could start going down the correct channels, and she'd be getting the right, she'd be in the system, you know. (l. 393 P02)

For most parents, it was helpful to learn about autism and understand their child's behaviour. This mother identified that it was useful to have the perspective of someone on the outside of the family who had some distance from the child:

I mean, [Service X]'s service is unique. That has helped such a lot, and understanding more about how Connor works, but also about children in general. I mean, I'm a teacher, I've learnt about child development, but it's so different, when you're living it, in that it's almost you're too close to see it sometimes, and then someone can come in and say, 'oh but this and this is what's happening', and 'so it is, oh, well if I did that, that would change the whole dynamic. Oh, it worked!' [laughs]. (l. 1462 P03)

This mother felt that she needed to be shown how to respond to him, and it wasn't enough just to read about what to do:

To deal with it, I feel like I am, you know, was equipped with strategies how to deal with it, while before, I just know that he has autism, but no support, or, and you know, just reading, reading on the internet, doesn't really [S: you need more than that]. Yeah, you need really to, you know, like, with [Service A], it was, er, it was Jane, you know, the nursery nurse, that, you know, she was showing me, so when you go, look how I will, and I could really see how, how change, you know, Freddy's behaviour and he stop it, and [2] yeah, so. So then I seen that yeah, it's working. (l. 376 P05)

Parents felt that having input and support earlier on helped them to understand their child, and gave them confidence to deal with new situations:

I think that's what [name of worker] and that taught me was, if you work hard enough, you will get an end. And there will always be issues that come up, there will always be problems that you have, and they will always be different to what you have dealt with, but as long as you've got the tools and the understanding to make the difference, then it's a lot easier. (l. 683 P07)

As well as practical suggestions, some parents reflected that it had been helpful to speak to people that understood autism, who could see the child behind the behaviour, and had hopes and ambitions for their child. This support relieved feelings of isolation and increased their self-belief in their role as parent:



And that was a lot of support to me as well as for Euan, but, it, but they were working hard with Euan, it wasn't, erm, as a side effect sort of thing, it helped me. But they were there to help Euan, and that in itself helped me, because you didn't feel quite as alone because you were dealing with, you know, people that knew strategies that worked, and you could put them in. (l. 660 P06)

Participants also identified how learning about autism had wider benefits beyond helping their child, such as helping them with parenting their other children, communicating with other families' children, or those that they came into contact with through their work:

We have done a number of courses on communicating with autistic children and autism in general and so on, and that also gives me an insight. I think what works for autistic people also works for other people, so I don't think it's wasted time, it's extra time, but it's not wasted time, because, erm, although our daughter is not autistic, what works for Tim to a large extent also works for her, and all children, and that's actually very helpful. (l. 933 P09)

However, professionals and services were not seen as universally positive, as was seen in theme A, where there had been a failure to recognise autism. It will also be discussed in theme D, *parenting in the eyes of others*, where some parents felt judged and criticised by workers they came into contact with. Some participants expressed frustration simply at the lack of appropriate services, or that they had long waiting lists before a child could be seen:

...she said, 'oh he is on the waiting list, it may take up to six to nine months for him to start', and I just felt like, what is the point of diagnosing him, if that, you know, like, the diagnosis doesn't mean, you know, the support and stuff. (l. 254 P05)

Additionally parents identified limitations in diagnosis as a way of understanding how to manage problems, because of the diversity of presentations of autism in different individuals. This mother is discussing her two sons:

They're completely extremes, it's really, it's hard to explain how different they are to each other. It's, there's just, even though they've both got the same problem, it's, they are vastly apart from each other, in their issues and their problems, and the way they behave. (l. 136 P07)

- **Cii) Reducing blame and building confidence**

In addition to increasing knowledge and enabling access to services, participants spoke of how obtaining a diagnosis helped them by reducing the blame they felt for their child's problematic behaviour (see journal article Chapter 4). Some parents valued having the label of autism in order to communicate to other people the cause of their child's behaviour. This was helpful in protecting them from criticism from other people:

...sometimes when we were out, and he would behave in a certain way, people would be, you know, so to me it felt good to say that he's autistic. I've only ever had to say that to, twice, but you know, just in case, it's a good thing to have. I've got a diagnosis. So we, kind of, pushed them for that. (l. 270 P08)

Parents showed a growing confidence in their parenting approach and belief in themselves as experts in their children, through demonstrating knowledge about their child and a deeper understanding of their needs:

I think it's important that I don't panic, or get flustered or, you know. I think it's important that I'm, sort of, like his rock, you know, I think he needs that. (l. 740 P08)

Well it's choosing your battles, and I think that's important, is knowing which ones to fight out and which ones to let her win, is the, is the... And it's finding that, sort of, balance...(l. 527 P04)

Participants also communicated confidence in their parenting when discussing how they set goals for their child:

All I can do is be honest with them, and help them through their life, and guide them. My aim is that when they're old enough, they will be independent, and they can live their own lives. It may never happen, but I have an aim, and that's my target, and I will work very hard to get there, for their benefit, not for mine, if that makes sense, so. (l. 625 P07)

Through understanding their child and how the autism affected them, participants also reflected on recognising the need to challenge the child, and to push their limits, in order to help their development. They acknowledged that this was not an easy or comfortable thing to do, and it therefore communicated confidence and belief in their parenting skills that they were able to do this.

I think because it's just me and him, that I've got so used to his behaviour, that I don't really notice it so much, and erm, I tend to bow to his foibles, perhaps some would say more than I should, but erm, I've seen the result of not, you know. But I do try and, erm, blindside him from time to time, you know. He used to like to go home a certain way, 'Dad, turn left, turn left, Dad', and so I started to change that. 'Oh, no, Dad, what are you, where are you going? Why aren't you turning left?' I say, 'no, we're going a different way' and now he's okay with that, he doesn't mind.  
(l. 469 P08)

Just getting her out and about, and having her, like, interact, and, I think that's what's important is bringing on her skills by not letting her shut herself off and, regardless of how difficult that may be... (l. 500 P04)

Parents also expressed confidence through recognising the importance of meeting their own support needs in order to be the best parents they could be:

...one of the questions, you know, how can I best help a child with Asperger syndrome, and the answer is support his mother [laughs]. I just read that, and at that point I thought, yes! That's what will help. (l. 1110 P03)

Parents recognised that they were unable to do the best for their child if they were not looking after themselves and feeling able to cope:

I think if you get eaten up with that. [2] It's hard enough as it is, without putting that, if you can do something about that, you know, then you should, because it's going to impact on everybody, and you really going, your life is not going to be worth living, erm, if you go down that route too much. And you need help, you know, you go and get help, when you need it. (l. 640 P06)

Some parents spoke of noticing growing confidence in themselves as a result of learning about ways to manage problems:

Some things in this life I'll never fix, some things just happen, but nine times out of ten, I try and be a little bit more considerate, and I think before I act. And that, kind of, escalated from the boys, just to my every day life now. I just, I think before I react to anything. Cos I, because I have to do it at home, I have make this conscious decision not to react, I tend to do it all the time now. And it's probably a really good thing to do, because it gives you that opportunity to think about what's going on, why it's going on, and why it's happening. Erm, and then you can rationalise it. (l. 1406 P07)

However, not all participants reported such growing confidence. In particular, P09 spoke about the limits of employing strategies to help her child, as they could be exhausting to implement and not always successful:

Of course, we've learned a lot about how to help him, with structure and visual timetables, and symbols to help him understand what he needs to do, but that's also very tiring. (l. 543 P09)

#### **D: Parenting in the eyes of others**

The fourth theme of *parenting in the eyes of others* emerged through the participants' recollections of being negatively judged or positively recognised for their parenting, at both a real and an imagined level.

##### **▪ Di) Criticism and judgement of child and parent**

Many participants talked about dealing with other people's reactions to their child and judgements on their parenting as one of the most challenging aspects of their parenting experience. As discussed in theme A, the difficulties in recognising the condition of autism often created situations where the child was criticised for their behaviour by their nursery or by the public:

Er, you know, I've had people say to me, only once or twice, [this town]'s not bad, you know, 'you need to take more control of your kids, or your daughter'. And I'm like 'sorry', I mean, you know, I'm thinking, can you not tell there's something a wee bit amiss with her, you know. (l. 161 P02)

Parents reflected on feeling criticised themselves when their child's behaviour was being disapproved of, expressing a sense of interconnectedness between the parent and their child. In the following extract, the parent described being in the supermarket with her child having a tantrum:

And this woman was, like, on the phone, 'sorry, it's just some horrible child.' [3] I stopped dead, Pete went, 'what's wrong?' And then he looked at me and, 'you just heard what she said, aye?' (l. 1222 P07)

This feeling occurred even in the absence of overt criticism, simply by imagining what others might be thinking:

The most challenging thing, the thing that I hate is when we're out, like, say we go to Ikea or anything like that, and we're sitting having something to eat, and Gill is loud and shouting about something, because she's not in her familiar surroundings, and the way that the other people stare, that's what I hate. Like that you're just, you're not giving her a row, and like, you know, that she's a really badly behaved kid, that's what I hate. (l. 418 P04)

In educational settings, participants talked about a feeling of being reprimanded by teachers for their child's behaviour. This impacted negatively on their parenting confidence:

...whereas nursery had just said to me, you know, he's kicked people, he's bit people, and I'd say, 'oh I'm really sorry', and they'd say, 'well lets hope he doesn't tomorrow', and I'd go, and I didn't know how to, and, you know, apart from say to him, 'you shouldn't do that, that's wrong', you know, 'we don't do that at nursery', and you think I know, but, somehow it was just all too much. (l. 835 P03)

...on every single day, the nursery staff asked me to collect Tim early from nursery, because 'he wasn't managing'. Those were their words, he wasn't managing, and because I was ill with depression at the time, it didn't occur to me that it wasn't Tim that wasn't managing, but the staff that weren't managing and so I, meekly and shame-facedly, went to collect Tim an hour to an hour and a half early from his two and a half hour nursery session, and brought him home. (l. 188 P09)

Some parents talked about experiencing open criticism from others, including social services, after a child protection referral (P05) and from a doctor, when seeking help for their child's behaviour (P06):

They were questioning my parent--, you know, parenting skills where, you know, I'm not thinking highly about myself, but, I'm doing, you know, like, my best and [S: yeah, uh-huh]. So that was really hard, yeah. (l. 83 P05)

So we'll be saying to the doctors, well, he's doing this, and he's really disruptive, and he's started peeing on things, and he's doing this and that, which he doesn't normally do. They don't recognise that, that is, if, I've had some, a doctor say to me, 'well, we've got to be careful that we're treating the child's illness here, and not the parent', which was, erm, that didn't go down very well, and I did, we have sorted that out between us since then, because I really wasn't happy with that. However, I went away feeling really rubbish, because, you go away questioning yourself, when you're already dealing with all this (l. 133 P06)

In the following extract, P08 describes being criticised by other parents who perceived him to be conceding to his son's demands:

In the end, I went 'no, I can't, I just can't, I can't, I can't', because he had taken it as far as he could take it, you know. And it's those situations, I think, with autistic children, where other parents don't understand. They're like, 'why are you being so soft, you know, such a softie?' and you're like 'no, I don't think so.' But it's very difficult to explain that to anybody, they just don't get it. (l. 1240 P08)

Although P08 acknowledged it to be difficult, it did not impact on his sense of self in the same way as for some of the other participants. Others described feeling sad, angry and upset about the criticism from others:

I can get upset obviously, because I think, you know, that she's not a bad kid. So that's the only thing is I get angry, then I get, and I can get upset, but I just think well, it's their problem. (l. 466 P04)

Both these parents talked about having confidence within themselves to deal with it, but the following participant noted the impact it had on other people she knew:

And, I've seen what it can do to some people because some people just don't. I'm quite a confident person, and some people aren't, and it really knocks them down, and I think, they may say it's an innocent comment, and a lot of people, I probably

did it, do you know what I mean? I probably did do it at one point, but they don't realise the harm they're doing to that person. (l. 1312 P07)

P05 felt that her experience of feeling blamed and judged related particularly to her ethnic background. She felt that people from her culture did not understand autism, and typically blamed the parents for their child's behaviour:

And to be honest, on, on the other, on the other side, me and my husband, we didn't really feel comfortable about sharing that with, I would say mainly with people from our background, whether here or back home in, in [country in Middle East], because they will not get it. (l. 737 P05)

She experienced blame from her extended family, as well as the wider community, and she indicated the negative impact this had on her sense of self. She said that it made her think that the autism had been caused by her not spending enough time with her son as a baby or because of her own 'autistic', unsociable personality traits:

So before the diagnosis I had a lot of people like blaming me, for, from my in-law family, and from just friends of people that we know, oh, it's just because he's not spent much time, or, should like, yeah. I feel like it had a, detrim--, it really affect how I feel, I had that feel of guilt that it's because of me, and then after the diagnosis, I had the feeling, all because of my genetics, and I had, for a while, I was thinking, I'm autistic... (l. 461 P05)

I'd been in a stage where I was thinking, it's because of me, you know, like, I was comparing myself and my husband, he's, he's very sociable and has hundreds of, I don't know, you know, like, a long list of friends, while I just maybe have 2 or 3 friends. And I start thinking, 'oh, maybe that's, it's just me, you know, like, he got it from me' (l. 240 P05)

This mother explained that she had experienced such challenges from her family-in-law that she decided to tell them her son had recovered from autism so that they did not question her any longer.

P05 felt that autism was particularly difficult for people from her ethnic background to understand because it was an 'invisible' disability (see theme A). Participants

commented that this lack of awareness and understanding was a factor in allowing people to make judgements of the child:

Because they look like normal children, people automatically think they have the right to turn round and comment on my child's behaviour. (l. 1309 P07)

People are not generally tolerant of autistic behaviour and are also generally ignorant of what causes, you know, why people might behave in an autistic fashion. (l. 997 P09)

Although all parents identified examples of feeling criticised and judged, this theme emerged most strongly for P09. She described how she felt the nursery and her extended family blamed her son's behaviour on her depression, which she internalised to some degree. Unfortunately, the resultant impact on her perception of herself continued to the present day:

...as the mother of a badly behaved child, instead of being the caring mother of a delightful child, I was gradually becoming a bad parent of a badly behaved child, so I faced a lot of personal criticism and hostility as a result of Tim's condition and my health has suffered significantly, my mental health has suffered significantly as a result, erm, and continues to suffer, although I now have a greater understanding of autism and also depressive illness, erm, but that is the reality for me. People quite often have, erm, condemned Tim, and me, and that is obviously not, not a good feeling. Erm, however unjustifiable, it's still hurtful. (l. 172 P09)

This extract highlights the interaction between her depression and her son's behaviour problems, in that they both affect each other. As well as feeling judged and criticised by those in her social world, P09 talked about a sense of being judged by 'society'. This was linked with a lack of recognition and value placed on the role of being a carer for a disabled child:

We have a particular difficulty and it makes, it doesn't make economic sense for me to have, to try and find work, and therefore have to pay for somebody to look after Tim, so I'm caught in that [2] position of being, erm, of really having no viable alternative but to look after Tim, erm, which of course I want to look after him, but my position as a full time carer is not respected by society generally as far as I can perceive it. (l. 440 P09)



It's difficult to keep a sense of myself. I'm an educated, well-travelled, well-read, formerly highly productive member of society, and now I am reduced to, whatever it is, seven pounds 56 a day, of contempt basically. It's quite a change, it's quite a change in status. (l. 1039 P09)

She identifies the impact this has on her sense of self, and comments that she has to work hard to preserve her self-esteem by reminding herself of the efforts she makes:

So I have to look to myself for my own self respect because I'm not widely, erm, widely acknowledged, what I do is not widely acknowledged, erm, in the way that somebody with a job in marketing or a lawyer would be, for example. (l. 1044 P09)

I have to guard against that, thinking 'oh poor me, this is all really hard', erm, and on a good day, when I'm, sort of, less depressed, I might think, 'well actually, to be blunt, nobody else does what I do, and if they did they wouldn't do it as well', and that sounds a bit arrogant but I do, I, part of me believes that, I have to keep saying it to myself, because, frankly, nobody else will say it. Erm, so I try and maintain a, some sort of healthy self-image, erm, but I am certainly not where I wanted to be. (l. 1061 P09)

This view of society is in contrast to the view of P08, who commented that the welfare system had allowed him to work part-time in order to be a single parent and support his son:

And actually, in this society, which is, you know, civilised, I am able, because it allows me to, to do this for him, you know. Because I only work part-time and I get support, you know, er, and tax credits and all the rest of it, so I can do it, and not panic about, you know, not being able to pay the bills. (l. 1478 P08)

## ▪ Dii) Recognition and evidence of parenting skills

The second aspect to *parenting in the eyes of others* was the sub-theme of feeling positive when parents' ability and efforts were recognised by others, or validated by the child making progress. For some parents, this was through recognition by professionals working with the child, for example, in schools, and was more highly valued if the child had been criticised or judged in the past:

I think it makes a huge difference if you know that other people like your child. (l. 1414 P03)

Last week, he came back with ‘Pupil of the Week’! [S: oh, bless] [laughs] So there you go. (l. 253 P08)

Participants also valued recognition from friends, partners, or family members:

What makes a difference to me is when somebody actually values what I do. So, for example, my aunt, my maternal aunt quite often pays me the compliment of saying, ‘the children are lucky to have you at home’... (l. 1020 P09)

Some participants commented on a feeling of confidence in their parenting coming directly from their child. P04 recalled a poignant incident signifying a turning point in her belief in herself:

...I remember being really, really worried about Gill, and I would take her out the back to play, and she would pace the same bit of thing, all the day, and then one day I remember picking her up to bring her in, and I remember her kissing me and saying, ‘I love you’, and from that minute on, erm, she would always say that, she would always cuddle me, and she would always call me her best friend. So I know that whatever I’m doing, I’m doing right, so that’s I suppose what gives me the confidence, that I know from her view, whatever I’m doing is right. (l. 802 P04)

Participants also drew on evidence for their abilities and skills as parents from the development of their non-autistic children:

So that as well helped, and I think after that, I think, it was mainly having Bobbie that, you know, like reassured me, and make me feel really positive, and that I am. (l. 1386 P05)

When parents were able to see that their child had made progress, they were often able to take this as evidence for their abilities, and this boosted their self-esteem:

I think I’m a good parent. People tell me I’m a good parent, so, but I do worry, you know. I perhaps don’t worry so much now as I used to, because I’ve seen him progress. I used to worry that he wouldn’t progress, that really did frighten me. But, erm, I’ve, you know, he’s been alive long enough now, for me to realise that, yes, he will get there eventually. (l. 1320, P08)

I suppose when things are going well, the satisfaction of, thinking, you know, he’s doing, he’s doing alright, and he’s happy and that’s, you know, it’s, it’s a great

feeling to, you know, see a happy child and think, you know, I had some role in that, and you know, it's lots of other things as well. But I'm not..., my mum reminds me, I'm not very good at sort of, taking the credit, but I tend to sort of think, oh, you know, school have done this, but when I've got an unhappy, cross or angry child, that's my fault [laughs]. (l. 1620 P03)

This parent highlights the difficulties for her being able to recognise her contribution to positive progress. It also suggests that it can be problematic for parents who do not see progress in their child. For P09, this has even greater significance given the investment she makes to her exclusive role as a parent:

As a full-time parent, rather than a, I mean I know all parents are full-time, but I mean as a person who spends all their time doing that, rather than has a separate career, I guess I've had more experience, not less than that, of other people, and I guess that's also a difficulty for me in the sense that I chose to be a full-time mum, I had the luxury of that choice, but I chose to do it, and then it seems in some ways I've made a big hash of it, I've done it very badly, because he is in some ways really quite a badly behaved child, and we don't really have, we don't have a good grasp on his challenging behaviour, we can't manage his behaviour particularly effectively, although we're learning to. Erm, so that's particularly galling to me. So my parenting style hasn't been as effective as I thought, as I hoped it would be. (l. 911 P09)

The absence of positive evidence of progress for this mother also interacts with her sense of not been valued by society as a carer as well as the general impact of her depression compounding her feeling of failure as a parent. Throughout the interview she struggled to have confidence in herself as a parent.

### **E: Dilemma of acceptance**

The final theme captured the ongoing dilemmas parents experienced around accepting the condition of autism in their child. On the one hand, accepting autism meant acknowledging the pain it had caused, and the loss this meant for them and their family both in the present and for the future. On the other hand, it enabled them

to reflect on how the experience had affected them positively and what their family had gained from it.

▪ **Ei) Acknowledging pain and loss**

Some participants spoke of experiencing emotional pain and loss on learning their child had autism, and in coming to terms with the implications of this. Although this theme did not arise in all interviews, it was strongly expressed in those that it did occur. Participants spoke of the shock and sadness of learning that their child had an underlying difficulty:

So, so it was a shock. [2] It's a shock in the fact that you don't want to hear it, you know, you don't want your kids not to be perfect. (l. 459 P07)

When it started to become clear to me that Tim was significantly different from his peers, I was absolutely terrified for his future, and crushed to the point of, it was like a tragedy to us, because everyone looks at their child, and has, er, wants them to be happy and safe, and without wishing to have any particular expectations of him, I hoped he would have an ordinary life that was as easy as possible. But when faced with a difficulty like autism, that's clearly not possible, and that is a massive, massive blow, to how you view your child's future and how therefore you view your own future. (l. 115 P09)

Some parents used a metaphor of physical pain to describe the feeling. They talked of a "massive blow" (P09), feeling "mortally injured" (P09), and being "like a punch in the stomach" (P06). Participants' expressed a feeling of loss for the child they had hoped to have, and it being a realisation of their greatest fears:

Yeah, having a daughter who's disabled, you know, and not what, you know, when we had kids, that wasn't what I thought having children would be all about. You know, I wasn't expecting that. And one of my worst fears was something like that, sort of happening (l. 294 P02)

Er, it does make you feel sad, you know, knowing that it's something that's never going sort of go away, you know. Like if you lost somebody like, you know, or a partner, or somebody really close to you, if they died, you know. (l. 504 P02)

Grief was also expressed in the sense of loss for the anticipated future of their child and family, or for what might have been:

Yeah, you start to get a view of [2], er, it's like, other people's lives are going on as they should be, out with yours. Erm, [2] things are normal for them, and sometimes you can get a bit resentful, because you, sort of, think, oh well, you know, Euan should be doing that now, or we should have a life like that as a family, we should be able to do that as a family. (l. 604 P06)

But there are times, that's what hits you, that's when I do get those days when, maybe just a little thing can happen, and you just think, oh, that's, our child's never going to be able to do that, or we're never going to be, experience that with our child or that. But usually I try and, usually we sort of try and turn it round to, 'well maybe that won't happen but this can happen or a different version of this', you know, because I think that's a more positive way of looking at it. But there are days when you're just not positive. (l. 1012 P06)

Although most parents spoke of a process of accepting their child and the condition and on reframing the negatives, they continued to experience feelings of grief and loss on an intermittent basis, such as on noticing another part of life that their child would not be able to participate in.

#### ▪ **Eii) Oscillating between fear and hope for the future**

The second sub-theme within *dilemma of acceptance* captured the participants' expression of their fears and worries for their child's future juxtaposed with hope and cautious optimism that they and their child could cope:

Well, I'm worried about schooling, and I'm having to do that just now. I've enrolled her at her, at, [identifier removed], our mainstream school, but I've also got a, arranging a meeting for one of these speech and language units, to have a look at them, because, because she stims to books, and I worry that it's books that they learn with, and how many hours learning support will she get? Will she get enough? Because what will she be learning when she's not there? Will she get picked on when she gets older? Lots and lots of things, but I know that Lianne went through a stage of getting picked on, and Graham's had hassle at school and I know I had hassle at school, and I think, well, you can't stress too much, because you don't, like, anybody can have that, so it's... Once I get her into a school, and I feel happy that she's happy there, then I'll be... but, but I don't stress anymore, it's not worth it, it's not worth the hassle. (l. 895 P04)

In this extract, this mother is articulating her worries about her child starting school, whilst at the same time commenting that she should expect her child to have difficulties, because she and her older children did. It concludes with her reflection that it is not worth getting stressed about, although it is apparent that she is still worried.

In the following extract, the father expresses fear and uncertainty about the future, and although he is optimistic given the progress his son has made, he emphasises keeping the existing services and support structures in place, reinforcing their importance in maintaining his son's development:

But I do also feel at this time in his life that, I still feel like I'm in the unknown, you know. I don't know what's going to, I don't know how it would be when he's a teenager, or older, or what, you know. [2] But I worry less about it now, you know, we'll work it out, whatever happens, we'll, we'll cope, you know. I don't think, well, I don't think he'll, I think he will go on and get a job and so on, but, I don't think anybody who's in the process of supporting him now should stop doing what they're doing, because I think if they did, it would be a completely different story. (l. 1330 P08)

In this final extract, this mother conveys her hopes for her son, along with the tremendous loss she feels about the impact of his condition:

It does pain me to sound negative about Tim, but I think I have a quite good understanding of his capabilities, and where he is less capable, erm, and I honestly believe that nobody hopes more than I do that he will develop, erm, to reach his potential, erm, but I also see his limitations very clearly because I spend most time with him of any adult. (l. 599 P09)

#### ▪ **Eiii) Meanings of acceptance**

The third sub-theme of this super-ordinate theme, meanings of acceptance encompassed the spectrum of ways that acceptance was expressed by the parents.

This ranged from finding autism difficult to acknowledge, towards a sense of resignation and tolerance, through to open and unconditional acceptance of the child. As with the above sub-themes, participants moved between these states throughout the interviews, illustrating acceptance as an ongoing process rather than an end point or absolute outcome.

P05 spoke of finding the diagnosis hard to accept when it was initially given, as the process of assessment had begun to reassure her that her child's language was progressing:

By the time they made the diagnosis, he was already having like 9 words, and I started actually to feel like 'no, he's progressing, he's fine'. Plus his dad was in so much denial completely that his son has any problem, [S: right], so I started to think, 'oh maybe he's fine, you know. Maybe I should just, you know, like, stop worrying'. So when they gave me the diagnosis, I wasn't really, I don't know. The paediatrician said 'you yourself mentioned autism', and I was like 'no, he's fine, he's...' (l. 208 P05)

Some participants noted differences between them and their partners' ability to accept the diagnosis, both at the time it was made and throughout their child's development. Participants variously indicated that their partners' difficulties with acceptance might be to do with feeling the loss of the child they hoped for, the fact that they could not be cured, or feelings of guilt that the child's autistic traits might have originated in them:

Erm, Charles struggled with the whole idea of..., for a long time, the idea that Connor was going to have a diagnosis, he didn't like that. Still doesn't like..., I mean I'm the one who's gone to the Help course and joined the [local autism charity], and got in touch with [Service X], and, Charles is very..., I get the impression very uncomfortable at first, I think partly because when we were reading about it, so much of the stuff was relevant to him (l. 975 P03)

And it took Tony longer than it took me. I think he, he spent a long, long time, longer than me, going 'why did this have to happen?' and, you know 'there must be something we can do to fix it' sort of thing. And getting distraught about it, for a lot

longer than I did. But then maybe out of the blue, I would get distraught about some silly little thing that had happened. (l. 1201 P06)

P06 illustrates the ongoing process of acceptance and how grief could be reappear at later points. The extracts above demonstrate how some fathers struggled to accept the diagnosis. Below, P09 explained that her husband was more able to accept her son's condition than she was, although he was in denial about it when she first recognised problems:

Mark's reaction was not nearly as emotional as mine, erm. [2] Mark has more of a religious belief than I have, and he said, and believes, I think, that Tim is as God intended him to be. So he can accept Tim in that sense, and I suppose I have come more towards that idea, that Tim is as he should be. However, it's a hard should. I don't want him to suffer, and yet he suffers. He suffers every day as a result of his condition. So Mark is, erm, more at peace with himself about Tim's condition than I am, because Mark access to a higher belief than I have, erm, access to, essentially. Before Tim's diagnosis, Mark was very much in the denial camp, in other words, there's nothing wrong with my child. When I first came back from the nursery saying he had no empathy, and I said, you know, 'do you think he might be autistic?' Mark said 'do not use that word outside of this house in case he gets labelled'. (l. 454 P09)

For many of the participants, acceptance was expressed through a sense of things being just the way they were, and that they just had to get on with the situation. This came with experience of their child and an understanding of what they could and could not change:

Yeah, well, you try, obviously you try to, to encourage her to stay or whatever, but if she's really uncomfortable in these situations, you just say, well, there's not much else we can do, we're certainly not going to lose sleep over it. (l. 75 P04)

But that said, do you know if, but that's what, kids are kids, you make the best of what you have, it just so happens that our kids are quite demanding, and we just have to work round it. It won't be forever, well, it might be, erm, we just have to wait and see. (l. 900 P07)



This extract hinted at a dilemma for P07. She expressed that she was able to deal with things in the present, by positioning autism as ‘it won’t be forever’. In reality she knew the autism was not going away.

P06 expressed strongly the responsibility of the parent to accept the child and get on with the task of supporting them:

So then, if you don’t accept it, and try and deal with it, you’re not doing the best for your child, and that’s your job, because you brought them here, so, that’s your job, in my opinion. (l. 615 P06)

At times, participants indicated a more positive and unconditional acceptance of their child’s difficulties that went beyond it being ‘just the way it is’:

They didn’t ask for this, they were born that way. They’re not bad people, they’re not cruel people, they’re actually lovely kids to be around. I don’t want to change them. (l. 582 P07)

She can have tantrums, and she can kick and bite and whatever else, but, it’s her, and I wouldn’t change her, so. I wouldn’t say it’s devastating because it’s not. (l. 308 P04)

P04 suggested that other people might assume it is devastating for her, or she implies that other parents she knows have used this term to describe their situation.

In the extracts below, P09 again expressed an oscillation of feelings of acceptance for her son, being grateful that he was healthy but wishing he was different. She accepted the role of his mother with a sense of both duty and fate, but her distress was apparent:

I guess for me the most important thing is I’m blessed to have two healthy children. He is not unhealthy, erm. I would never send him back, erm, I would, er, it sounds awful to say it but I do wish he was not autistic, because, er, when I say awful, it’s

like I'm not accepting him for who he is, but I, I can see a boy in him that is not autistic, and I would have liked for him to have an easier life, (l. 1088 P09)  
I do believe that Tim is for me, [3], because nobody else would love him as I do [crying]. (l. 1114 P09)

▪ **Eiv) Finding positives and discovering rewards**

The final sub-theme of *dilemma of acceptance* represented the participants' discussion of the benefits and positive outcomes of their experience of parenting a child with autism. These arose implicitly through evaluating the child relative to others:

I mean, and a lot of other kids we meet, who are like at school with her, she's actually a lot better than some of them. Some of them are, you know, this is when we think, Christ, it could have been so much worse, you know. (l. 584 P02)

My mum always said that as well, you know, that some of the brightest children she's had in her class have been autistic children. The brightest child she's ever met was an autistic child, she said, so, you know, it's, it doesn't mean, it's not the end of the world... (l. 278 P04)

Participants also looked for positives in their situation as an explicit attempt to cope with the experience.

I think Chris's the same, we feel really, really blessed that, you know, that, we were given the child that needed our help and support, and who we can help and support. (l. 951 P04)

I tend to be quite positive anyway, or I always try to be positive. So I look at the positive in my kids and not the negative. Yes, there are things I don't like them to do, but they're great kids. (l. 613 P07)

That is what we focus on, I suppose, and that's what makes it different. That I take the bad, because everybody's got a nightmare in them, and erm, but we just focus on the funny things about her, and the good, the things that make us smile, and there's so many of them, that, you know, that it's, erm, you don't even think about the fact that it's tough. (l. 1065 P04)

P06 explained how she dealt with feelings of loss and distress triggered by certain incidents by deliberately trying not to think about them at the time, and then coming back to them later to reframe them positively:

Well, sometimes a thing will happen and it does really look like, it's like a punch in the stomach, but you'll think, this isn't a good time, because I've got this to do, her to get to this group, this to do and that to do. If I start thinking about it now, I'll get really upset, and not be able to do what I'm doing. So, hmmm. So it will kind of stay in the back of your head until you've maybe got a quiet time at night or something, and then allow yourself to think about it.

S: And then?

P: And sometimes it's not quite as bad. If it's there in the back of your head for a bit, and you're, kind of, thinking about it a wee bit during the day. This sounds a bit strange, doesn't it? [S: no, no it doesn't] But it's just how I deal with it, so it's kind of in the back of your head, and then when you do allow yourself to think about it properly, or you've got the time, you know, at night, because there's always some--, mad in here when the kids are here, erm, it maybe, you've had a little bit of time to, kind of, come to terms with it, before you've even started thinking about it, so it doesn't seem quite as bad. Or you can tell yourself, you've thought of something a wee bit positive that you can chuck into the mix, so [laughs], it doesn't seem as bad.

(l. 1040 P06)

Some participants also found positives by noting that the experience had had a positive impact on their relationship with their partner.

No, if anything, it probably brought us closer together...(l. 317 P04)

Participants commented that their child and the whole experience had helped them by putting things in perspective, and making them realise what was important in life:

You know, it's probably actually been good for us in our lives, you know, it's probably done us some good, you know, cos probably took quite a few things for granted beforehand. (l. 530 P02)

I think Gill has, erm, Gill has probably helped me become a less stressful person, because, as I say, she makes you take the time to stop, and, and you do, you think, well there's far more important things, like, so what. And like that's possibly what, what's helped me become less stressed and, because I would always, I would be ill for months thinking about things like that before, but not with her, no, I think she's shown me something different. I think she's taught me a lot more than I could ever teach her, definitely, definitely, she's taught me more. (l. 918 P04)

P04 talked about how her child had helped her to see things in a different way, including noticing natural wonders and beauty in simple things.

Appreciating life, whereas before I think you did everything at, you never really paid much attention, just, you know, everything was like, go, go go, go, go. And you never really stopped to, I guess, to, sort of, you never stopped to, sort of, appreciate anything really, and I guess with Gill, the way that she'll walk along the road, and she'll stop and, she'll look at the smallest thing, and do shapes in it, and then, like, it'll be the raindrops on the window, or whatever, and she'll see things in that, and, so it does, it makes you stop and it makes you appreciate. (l. 871 P04)

P06 also valued the view that their autistic child had about the world, and that they would speak their mind:

Well, the best thing about being his mum is, I think that a mum of a child with autism is they're just so honest. You know, there's no, none of the under, underlying things going on, they're just as they are, they'll tell it like it is, you know. Don't want to do something, they'll say no, and there's no underlying things going on. (l. 1295 P06)

Participants described recognising the value of small steps forward, or achieving goals that might seem trivial to other families, but for them were greatly significant.

It's quite nice to appreciate the little things, like Michael when he first said 'Mum'. That meant more when he said 'Mum' when he was five than it would have done when he was one, if that makes any sense, because there was more meaning to it. (l. 1391 P07)

I mean, I couldn't believe it, the first time he ate fish fingers, I was amazed, I was just holding onto the table and not, I didn't want to get too excited, because I thought, if I get too excited, he might never do it again. Being very casual, and the same with pasta, he sat in this house and ate the pasta, cos he would never have eaten before, unbelievable. (l. 1190 P08)

Participants also indicated the satisfaction they felt knowing that they had been able to cope with what many would find a difficult situation, and this gave them confidence in their parenting:

And also a positive is [2] that I've learnt that I'm quite resilient [laughs], and that I can deal with quite a lot of, er, not-so-good things that happen, [2] when a lot of other people can't. (l. 1313 P06)

Participants also communicated their confidence in themselves through identifying the role as satisfying and worthwhile:

I suppose, you know, just being able to deal with her and feeling comfortable with her, I guess is like an achievement in some respects, you know. That, er, I've been given the opportunity to sort of, er, get involved with her, that's come to me in my life. (l. 978 P02)

I think, erm, [2] that it's hugely worthwhile, and that, erm, although I was quite successful in my career, it matters nothing compared to what I'm doing now. (l. 1467 P08)

P03 made sense of her role as a parent as helping her child's personality develop at a deeper level, which she found greatly rewarding.

Erm, [3], I suppose just, I suppose it's almost on a spiritual level, it's that another, another person. (l. 1613 P03)

Many participants commented that it was a rewarding experience to have those moments of connection with their child, and to witness in their child's joy.

Erm, he is completely uninhibited in his joys and he does not have the ability or the desire to lie, so he will say very sweetly, we've taught, we're trying to teach him to express his emotions, so he might jump up and down, and now is able to say 'I'm excited, Mummy, I'm excited', with such pure rapture on his face, that it's impossible not to be delighted for him. (l. 864 P09)

He's completely unbridled in his joy of life. Erm, and so when he's happy, I'm happy, [crying] and often when he's unhappy, I am not happy, not always because I understand that really there's not, I can't solve all of his problems, so he, he is at the same time, the light and the darkness of my life. But mainly the light. (l. 882 P09)

This extract from P09 captures again the dilemma of acceptance, through her experience of her son as encompassing the greatest rewards and the most intolerable pain (the 'darkness').

## Chapter 6: Additional Discussion

This study used IPA to explore the experience of parenting a child with autism, and the impact of this experience on parental sense of self. The characteristics of autism being hard to know and understand, and being all-consuming and extreme were highlighted as important in impacting on the parent's sense of self in terms of doubting one's judgement and having confidence. The literature particularly relating to these two themes was discussed in the journal article in Chapter 4. Other aspects of the parents' experience of parenting a child with autism that related to a sense of parental confidence were the impact of diagnosis, other people's perceptions, and processes of acceptance. The respective themes will be discussed below in relation to the existing literature.

### *Diagnosis giving understanding and confidence*

After the confusion and uncertainty of the presentation of autism in their child, parents said that diagnosis was helpful in giving them a focus, access to services and something to do, which gave them more confidence in their approach. Similarly, Midence and O'Neill (1999) identified the value for parents in having a label for their child's difficulties in helping them know what to do. Ryan and Runswick Cole's (2009) paper on parents' advocacy and activism also highlighted the significance of being active and doing something practical in response to the diagnosis, although advocacy itself was not a prominent theme in the present study. Gray's (2006) longitudinal qualitative study exploring coping in parents with children with autism suggested that over time parents move from active coping, such as reliance on services, to emotion-focused coping, e.g. appreciation of child's good

qualities. The present study highlighted the co-existence of these strategies for many parents at a single point in time.

### *Parenting in the eyes of others*

Participants identified how other people's perceptions of their child and their parenting impacted on their parental self-confidence, in both positive and negative ways. Real or imagined criticism and judgement by others impacted negatively on feelings of confidence, and recognition by others had a more positive effect, through parents feeling valued by others and their child, and seeing their child progress.

Research by Schall (2000) similarly found the theme of discrimination by the community to be significant for the parents interviewed, who reported experiencing judgements by others about their competence as parents. Rocque (2010), in his analysis, argued that one of the roles of the mother of a child with autism is in mediating the interactions between the child and broader society, although he did not explore the impact of this on the parent.

Support for the theme that recognition and evidence of parenting skills increases confidence comes from Bandura's (1982) concept of self-efficacy. Bandura identified the importance of the role of enactive mastery, that success through actual experience is a powerful predictor of self-efficacy, such as when parents can see evidence of progress in their child. Conversely, self-efficacy is affected when progress is not seen, perhaps more likely when the child has an all-consuming and hard to understand condition. Corman's (2009) study suggested that the absence of

positive and satisfying experiences of parenting might impact on coping and parental well-being.

### *Dilemma of acceptance*

Processes of acceptance were identified as significant in the experience of parenting a child with autism, and have also been widely reported in the literature. With most parents interviewed, there was evidence for the view that parents do not reach an end point of acceptance of their child and their condition, that it is an ongoing process (Featherstone, 1980). Carter and McGoldrick (1980) discuss how families commonly revisit grief and adjustment at times of transition in the life cycle, such as when children start school, or leave home. Rather than an absolute resolution, families experience 'chronic sorrow' (Olshansky, 1962), and parents may feel frustration, sadness, guilt and remorse at times when they are reminded of their child's differences.

Similar themes to dilemma of acceptance in the present study were identified in qualitative research by Myers *et al.* (2009), Kearney and Griffin (2001), and Altieri and von Kluge (2009). Myers *et al.* labelled it as 'my greatest joy and my greatest heartache', describing how parents find positives while acknowledging stress. Although interviewing parents of children with developmental disabilities rather than autism, Kearney and Griffin similarly identified a tension in the discussion of experiences of both joy and sorrow in the parents they interviewed. Altieri and von Kluge represent this dilemma within the themes of 'devastation' and 'growth',



acknowledging the distress caused by the diagnosis, along with the growth and benefits parents had experienced as individuals and as a family.

Discovering rewards was also central to Corman's (2009) research on the positives of care giving, and included parents seeing their child progress, and observing joy in their child. One of the benefits identified by parents in the present study was also reported by Woodgate *et al.* (2008), where parents felt that experiencing autism in their child had helped them to put things in perspective and appreciate the small steps made. This was similar to King *et al.*'s (2009) study on family belief systems in parents with a child with autism or Down syndrome, which identified worldviews in parents of optimism and openness to experience, acceptance (of the challenge), and appreciation (of life). This also links to the concept of benefit finding reviewed in Chapter 1 (Samios *et al.*, 2009), which was suggested to link to positive affect and life satisfaction in parents.

Hastings and Taunt (2002), in a review of positive perceptions in families with a child with a disability, found that positive perceptions do co-occur with negative and stressful experiences, and argue that they can serve a function in coping and adjustment processes. In the present study, the discussion of positive perceptions also indicated confidence in the parenting role.

## **Overall themes and theories**

### *Ambiguous loss*

Ambiguous loss theory (Boss, 2007) was identified to be particularly relevant in examining and making sense of the overall accounts of these parents' experiences. Ambiguous loss describes a loss that is uncertain, freezing the grieving process, and blocking coping and decision-making. O'Brien (2007) argued that loss can be experienced as ambiguous in families with a child with autism, due to a lack of clarity over the diagnosis, difficulty in predicting outcomes, variability in day-to-day functioning, outward appearance of normality, and loss of relationships. All these aspects of ambiguity were apparent in parents' perceptions of their experience, through the theme of autism being hard to know, recognise and understand. Ambiguous loss helps to make sense of how the unique experience of parenting a child with autism impacted on coping and led to self-doubt in the parents. For example, difficulties in understanding and communicating with the child lead to ambiguities in the parent-child relationship, with parents feeling uncertain about what to do. Ambiguous loss is also relevant to the theme of dilemma of acceptance, capturing the tensions implicit within acceptance of acknowledging pain and loss, along with looking for hopes and rewards from the experience. O'Brien also described the process of identity ambiguity which can result from ambiguous loss, where there is a blurring of boundaries and ambiguity in the roles and responsibilities of the parent and child. In the present study, this was seen in the theme of parenting in the eyes of others, where parents experienced a sense of interconnectedness with their child, meaning that a criticism of their child was felt as a criticism of them. Identity ambiguity could also be a way of understanding the theme of autism as all-consuming and extreme, pervading boundaries of normal family life.

The parents' perceptions of their experiences of autism in the present study align well with a conceptualisation of ambiguity. However, three out of eight participants did not perceive their experience as a loss, and the majority of parents interviewed felt that they were coping well. Therefore, the concept is helpful for understanding why autism may be particularly difficult for families to deal with, but does not account for variation in coping and adjustment within this group of families.

### *Sense of coherence*

The concept of sense of coherence (Antonovsky, 1993) was relevant to an overall account of these parents' experiences. Sense of coherence is described as an orientation or way of seeing the world, which facilitates successful coping in the face of adversity by perceiving the experience as comprehensible, manageable and meaningful. As discussed in Chapter 1, Samios *et al.* (2008) developed a scale applying this concept specifically to the experience of parenting a child with Asperger syndrome. This was labeled sense making, and is defined as the search for meaning, understanding or coherence in difficult experiences. In the present study, the concept of sense making or sense of coherence related to themes of parenting as an impossible task, diagnosis giving understanding and confidence, dilemma of acceptance and finding positives and discovering rewards. Relating back to ambiguous loss, it also suggests why autism is more difficult to cope with, being uncertain and hard to know, making developing a sense of coherence more problematic.

Although sense of coherence was not quantitatively measured in the participants in this study, it seems likely that those parents volunteering to be interviewed about their experiences would have a more developed sense of coherence. Most parents interviewed appeared to be coping well with the experience on the day of the interview, with the exception of P09 who perceived it to be comprehensible and meaningful, but perhaps not manageable at the time. That the person believes they have the resources to cope with the situation is an important aspect of sense of coherence.

#### *Other relevant concepts*

##### *Resilience*

Most of the parents in the present study showed evidence of resilience, through acknowledging that they were coping well with what was a challenging experience. Patterson (1991) identified ways of promoting resilience in families with a child with a disability. Some of these, including maintaining a positive outlook, finding meaning in the face of adversity, and actively seeking out resources and opportunities, relate to the themes that emerged in the present study.

##### *Attachment*

Attachment theory (Ainsworth *et al.*, 1978; Bowlby, 1969, 1982) is a central concept in understanding child development and the development of healthy child-parent relationships. A secure attachment relationship between parent and child develops through the caregiver's understanding of, and responsiveness to, the child's distress, helping the child to learn how to regulate negative emotions. As communication in a

child with autism is impaired, this may have implications for parent-child communication and development of attachment relationships. Common issues in families with a child with autism, such as challenging behaviour, or parental depression and stress, may lead to further barriers.

In the present study, the theme of autism being hard to know and understand highlighted the difficulties and frustrations for parents trying to connect with and understand their child. In examining the evidence for attachment difficulties in children with autism, Rutgers *et al.* (2004) reviewed studies on observed attachment security in children with autism for a meta-analysis. They concluded that children with autism were able to form secure attachment relationships, but the parent-child relationship was less flexible and sensitive, and represented fewer synchronous interactive behaviours compared to controls. This was thought to be the result of the social communication impairments of children with autism. Consideration of the attachment relationship in a psychological assessment in these families may therefore be relevant in understanding family presentations and formulating interventions.

### **Implications and recommendations for clinical practice and services**

Barbour (2000) advocates how qualitative research can contribute the evidence base of clinical practice through being theoretically useful in understanding phenomena, perhaps by providing an alternative perspective to ‘conventional wisdom’. The present study has relevance for clinical practice for those working in autism assessment and diagnostic services, as well as those directly supporting and providing interventions to families with a child with autism.

The theme concerning autism being hard to know and understand highlighted the struggle of many parents to get their child's difficulties recognised and to start the process of assessment. Frustrations about not feeling heard, anxiety and self-doubt all impacted on the parent's sense of self as a result of this. Professionals working in this area may be offering reassurance to parents about their child with the best of intentions, but the analysis suggested the importance of workers listening to the parents' concerns, acknowledging that parents know their child best, and validating their experiences and opinions. Clinicians conducting autism assessments should also be aware of the journey that parents may have been on to get to the point of assessment, and their feelings of guilt and self-doubt along the way, and approach the assessment with openness and sensitivity. At the same time, referral pathways to diagnostic assessment within the locality should be promoted across relevant frontline services, and waiting times for assessment reduced.

The theme of autism being all-consuming and extreme is also helpful to consider for clinicians during the assessment process. The process of taking a child's developmental history and synopsis of the child's current presentation through a parental interview may be extremely difficult for parents, as it requires them to discuss specific details of what for them may be an intense and overwhelming experience. Again, sensitivity and consideration of questioning can be helpful in reducing distress during this process.

It is hoped that an awareness of all of the recurrent themes in the present study will be helpful particularly to those working with parents with a child with autism, in order to gain a greater understanding of their experience, and to help to validate and normalise some of the difficult emotions or beliefs that parents may be expressing. This includes not only clinical psychologists and other mental health clinicians working in Child and Adolescent Mental Health Services, but also other health workers who commonly work with these families such as paediatric speech and language therapists and occupational therapists. An enhanced understanding of parents' experiences would also be valuable to staff working in educational settings, social work and voluntary sector services, and training could be given to these groups. Concepts of ambiguous loss, the dilemma of acceptance and ongoing processes of grief may be of particular interest, and be helpful in preventing staff from presuming that acceptance or resolution of the diagnosis has been achieved.

The importance of making meaning and a sense of coherence from the experience highlights possible avenues for clinical intervention with these families. Although therapeutic work may be useful on an individual level, group interventions could be more powerful through the validating experience of meeting other parents going through similar challenges and emotions. Psycho-educational interventions aimed at improving understanding about how autism may affect a child could also contribute to a parent's sense of coherence. This should be delivered in a way that promotes parental agency and self-efficacy, rather than merely providing knowledge, which has been found to be unhelpful (Kuhn & Carter, 2006). Group methods used in evidence-based parenting programmes such as 'Incredible Years' (Webster-Stratton,

2011), including short film case vignettes, ‘Socratic’ questioning, role-play scenarios and ‘homework’ tasks, could be incorporated. Peer befriending may be used to complement this, further promoting coping and development of social support networks in parents. These interventions should be evaluated and followed up in order to ensure that they are as effective as they can be.

In terms of interventions for improving challenging behaviour, the theme of parenting in the eyes of others highlights the importance of parents experiencing success in the strategies they try, and seeing progress in their child as a result of their efforts. Parents coming to psychological services for help with challenging behaviour often feel demoralised and ineffective, thinking that they have ‘tried everything’ and ‘nothing works’. At this point, the focus of the clinician should be on a thorough psychological assessment and formulation of the problem, to direct to the strategy most likely to produce any small change in the child’s behaviour, so that the parent is able to see progress and have more confidence in their ability. Again, interventions that promote parental agency, such as the ‘Incredible Years’ programme, will be most helpful here.

In terms of promoting coping and resilience, it may be helpful in clinical sessions to ask parents about their child’s positive attributes, what they have gained from their experience, and what can be rewarding about parenting their child with autism. However, this should be done sensitively in a context of listening and validation of difficult experiences and emotions.



## **Methodological critique**

Methodological limitations to the present study are considered in the discussion section of the journal article in Chapter 4.

As discussed above, this is the first known study that used IPA to explore experiences of parenting a child with autism, and the work has endeavoured to maintain strong methodological quality through adherence to criteria from Yardley (2008) and Smith (2011). This included a clear focus, strong data, and a rigorous, plausible and coherent analysis. Themes were elaborated on, interpreted and evidenced through extracts representative of the whole sample. The study has offered some interesting insights into the experience of parenting a child with autism, and the clinical implications of these have been discussed.

## **Future research**

As discussed in the journal article (Chapter 4), longitudinal qualitative research would be useful in looking at the experiences of parents at different points in time in order to gain a greater understanding of perceptions of parenting at different points of adjustment. It would also be interesting to look at the experiences of couple dyads, exploring differences between mothers and fathers, as well as the interactions and influences between them. Although there was some diversity in the present sample, it would be valuable to further explore the experiences of parents from different ethnic backgrounds and family constitutions (e.g. single parent or stepfamilies).

Quantitative methods could also be used to complement the in-depth understanding gained through qualitative research. Further research assessing perceptions of parenting, employing measures of parental self-efficacy or sense of competence (e.g. Teti & Gelfand, 1991), sense of coherence (Antonovsky, 1993), sense making (Samios *et al.*, 2008) and benefit finding (Samios *et al.*, 2009), and relating these to outcome indices of coping, adaptation or resilience, would be useful in understanding variations in coping and adjustment in different families. However, this requires further work on demonstrating the psychometric validity and reliability of these measures, as well as consistency in the scales chosen to assess coping and adaptation (as discussed in the systematic review in Chapter 1).

### **Researcher's personal reflections**

As mentioned in the methodology section (Chapter 3), reflexivity is an important aspect of doing IPA research. Throughout the research process I kept a reflective diary in order to detail my thoughts and feelings throughout the research process. This drew attention to influences of anxiety and other strong emotions, my own interests and biases, and the interaction between my research and clinical work, as discussed below.

As I was producing a doctoral dissertation on a research method I had not used before, I was anxious about the standard of the work I was doing:

I have my first pilot interview today and I'm feeling nervous. I'm worried about whether I'll get 'rich' enough data for the analysis, I'm worried that my questions won't generate the reflection/ discussion that I would like. But I guess that's why it's called a pilot.

I'm concerned that my project isn't original enough, and that in my quest to be original (looking at parents perceptions of their parenting capacity etc.) that IPA isn't the right thing to be doing to get that information.

I feel a huge responsibility – to these parents who have volunteered their time to me, as people who want services to be better for their families, as I guess that is probably their motivation. I hope that what I do is good enough. (31/10/2011)

The diary allowed me to reflect on the motivations, assumptions and interests I was bringing to the research, as discussed in Chapter 3, including the work I have done in private, voluntary and health service settings. I was also able to identify some of my biases:

My own prejudices at work today, [in a] part of [this town] that is not so well off, this mum might be more stressed, all-consuming role coping with this challenge. How wrong I was. The most positive, genuine reflections, I felt quite humbled by her approach. That she had got so much herself out of it, and wouldn't change her child in any way. What a contrast. What a contrast to the 'disappointment' [from an earlier interview]. It was surprising as she started off so negatively – what is she [the child] like? Stubborn! But what a refreshing, joyful parent, acceptance, not resignation to her daughters needs. (14/11/2011)

As the research progressed, I became more confident in my abilities in the approach I was using, as well as the suitability of it as a method for answering the research question.

I came out of this interview feeling more positive – I think because I could see her making sense of her experience, and I could make sense of that! (28/11/2011)

The reflective diary helped me from becoming overwhelmed by the experience, particularly when I was working on the data analysis. On reflection, I realised at one point that I was experiencing emotional transference from the interview with P09, who was struggling with her son, and that the themes emerging about her experience were mirroring my feelings about the process of analysis.

Emotional transference from the interview – feelings of being overwhelmed, challenged, relentless... (20/03/2012)

I was acutely aware throughout the interviews of the need to balance my role of researcher with my experience and skills as a clinician. Although I was mostly able

to resist the temptation to ask therapeutic questions, and keep to the interview schedule, the need in me to help others was sometimes too great:

Though at the end I did not manage to keep myself from falling into clinician mode – have you tried OT [occupational therapy]? (28/11/2011)

I experienced this sometimes as a dilemma in terms of the commitment to the method of exploring people's in-depth experience, but knowing that my role outside the interview was one of being part of the 'system' that the parents were often criticising. However, I also found the research process was professionally beneficial, particularly as I was on placement in a child learning disability service at the time:

I feel that I have learnt so much from these interviews about the experiences of these parents, and hope that it provides me with sympathy, empathy and respect when working with these families. These parents feel guilty enough and judged enough without professionals stirring it up as well. (12/12/2011)

Through these extracts and the research diary, I have attempted to document the development of ideas around my thesis, and the influences I brought to my analysis. However, as argued by Bishop and Shepherd (2011), there are limits to the process of reflexivity, and to self-awareness. I cannot know how I was perceived by my participants, and what influence that had on them, although I did try to reduce the salience of my role within the service that I had recruited them through.

## **Conclusions**

As the first known study to use IPA to explore experiences of parenting a child with autism, this research has provided a richer understanding of self-perceptions of parenting and the impact of these experiences on a parent's sense of self. This has contributed to a broader literature on positive adjustment in families with a child with autism.

Key themes included experiencing autism as hard to know and understand, and experiencing autism as all-consuming and extreme, which related to parents' feelings of self-doubt and blame, and a belief that their task of parenting was impossible. The importance to parents of a diagnosis in giving them understanding and something to do was another recurrent theme, and highlighted how the diagnosis could reduce self-blame and promote parents' confidence in their ability. The theme of parenting in the eyes of others represented the way that parents experienced and internalised negative criticism and positive recognition by others of their parenting skills. Finally, tensions and dilemmas of acceptance of the child with autism, through acknowledging the loss whilst recognising positives and rewards, was identified in developing a sense of self as a parent.

It is hoped that appreciation of the impact of the experience of autism on parental self-perceptions can enhance the way that those working with these families engage with parents and support them more effectively.

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## **Appendix 1: Invitation to participate in research**

### **Email to service mailing list**

One of our Board Directors is also a Clinical Psychology student at the University of Edinburgh. For her thesis, she is conducting research with parents on their perceptions of being a parent of a child with an autism spectrum disorder (ASD), and is looking for volunteers to participate.

“I would like to meet with parents (mothers or fathers) who have a child who has been diagnosed with ASD for at least a year. Other than that, it doesn’t matter how old your child is. I would like to interview parents, on their own for about an hour, about how having a child with ASD affects how you think about yourself as a parent. It might not be something you have really thought about before, and there isn’t much research about it, which is why I’m interested in it. I hope that the research findings will help professionals to better understand and improve how they work with families with a child with ASD. Please see the attached information sheet and contact me if you would like further information, or would like to volunteer.”

Thank you in anticipation

## **Appendix 2: Research Information Sheet**

*“Perceptions of being a parent of a child with an autism spectrum disorder”*

Researcher: [name given], Doctorate in Clinical Psychology, Postgraduate Student, University of Edinburgh

You are being invited to take part in a research study. Before you decide if you would like to participate it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with anyone you choose.

***Please do not hesitate to contact me if there is anything that is not clear or if you would like more information. Thank you for reading this.***

### **What is the purpose of the study?**

I would like to find out more about how your experience of having a child with Autism spectrum disorder (ASD) affects how you think about yourself as a parent. To help me do this I would like to meet with you and ask you some questions about your experiences.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time during the interview process and do not have to give a reason. You can choose not to answer any question that I ask. A decision to withdraw at any time, or a decision not to take part, will not affect any care or services that you receive. It will not, positively or negatively, affect the service received from [name of service].

### **What will happen if I agree to take part?**

If you agree to take part I would like to meet with you to ask you some questions. The meeting will take place either at the [name of service] Office, or at your home, and should last no longer than 1 hour. I will only need to meet you once for the interview. The interview will be recorded so that I can transcribe it later. The recording will be kept in a secure place and when I transcribe it I will ensure that any information (such as your child's name) that might identify you is removed. The original recording will be destroyed once the research project has been fully written up (approx. September 2013). Once I have analysed your interview and summarised my findings I would like to ask you for some feedback to make sure that I have accurately understood what you told me. Either we can meet again to discuss this, or you can write feedback down and send it to me.

I will also ask you to complete a short questionnaire to provide me with some basic background information about your child, such as their age, their diagnosis, and what kind of school they go to.

Once the study is complete, I will send you a summary of the results.

### **What are the possible benefits of taking part?**

It is not expected that there will be any direct benefits to you of participating in this research, although some people find it helpful or interesting to have the opportunity to talk about their experiences. I hope the study will provide a general benefit to services and parents by continuing our understanding of the impact of ASD on the family. In particular, I hope that it will be useful to workers and services seeking to engage and work with parents of children with ASD.

**What are the possible disadvantages of taking part?**

Some people can find it upsetting to talk about their experiences. I do intend to conduct these interviews sensitively, with the utmost care and respect to those who agree to speak to me. I also appreciate that you will be giving up some of your valuable time to speak to me.

**Will my taking part in this study be kept confidential?**

All information that is collected during the course of the research will be kept strictly confidential. It will not be shared with the [name of service] workers. Any information about you (including interview extracts) that are used in the final written report will be made anonymous so that you cannot be recognised from them. The only time I would have a duty to share information would be if you told me something that made me concerned that a child was at risk of harm, or that you were going to hurt yourself or someone else. If this situation arose, I would try to talk to you about it first.

**What will happen to the results of the research study?**

The findings will be presented to the board and staff at [name of service] and other interested services, e.g. in the NHS. The results may also be shared with wider services through research publications and conferences.

**Who has reviewed the study?**

This research project has been reviewed by the University of Edinburgh Clinical Psychology Programme team. It has also been approved by [name of service] Board of Directors.

**Contact for further information**

If you would like to talk a bit more about this study before deciding whether to take part, you can contact me [name given] on [telephone numbers given]. If you would prefer, you can text me with your contact details, so I can phone you back. Alternatively you can email me: [email address given].

My supervisors on this project are:

- [Academic and clinical supervisors named]

If you would like to discuss the research with someone independent of the study, please contact Heather Wilkinson, Director of Research and Knowledge Exchange, School of Health in Social Science, [email address and telephone number given].

If you would like to take part, please email or telephone me [name given], with your name, address, telephone numbers and email address if available. If you would

prefer, you can complete the enclosed sheet with your contact details and give it to your project worker to pass on to me so that I know that you are interested. I will then get in touch with you to organise a meeting.

Thank you for taking the time to read this

[name given]  
Trainee Clinical Psychologist  
University of Edinburgh

### **Appendix 3: Further Support Handout**

Information from [www.parentingacrossscotland.org](http://www.parentingacrossscotland.org)

#### **ParentLine Scotland**

**0800 028 2233** (free from a landline, mobile charges vary)

For any parent or carer in Scotland who needs information or simply someone to talk to. It offers support and guidance on problems including bullying, problems with teenagers, physical and sexual abuse, and dealing with difficult behaviour.

Open: Mon, Wed, Fri 9am-5pm; Tues, Thurs 9am-9pm

#### **National Autistic Society Autism Helpline**

**0808 800 4104** (free from a landline, mobile charges vary)

Impartial, confidential information, advice and support to people on the autism spectrum, their families, professionals, researchers and students.

Open: Mon to Fri 10am-4pm

#### **Contact a Family**

**0808 808 3555** (free from a landline, mobile charges vary)

Information, advice and support to parents and carers of children with any special need or disability.

Open: Mon to Fri 9.30am-5pm

#### **Kindred Scotland**

**0131 536 0583** (landlines charged at standard rate, mobile charges vary)

Provides advice and information for parents and families who are looking for help with their child's additional support needs. They provide a telephone helpline service for parents and are happy to answer any questions (Kindred was previously known as SNIP).

Open: Mon to Fri 9.30am-4.30pm

#### **Lone Parent Helpline**

**0808 801 0323** (free from a landline, mobile charges vary)

For any single parent needing information or advice, including personalised benefit calculations, information about returning to work and childcare, factsheets and local sources of help.

Open: Mon to Fri 9.30am-4.30pm

#### **Advice Service Capability Scotland**

**0131 313 5510** (landlines charged at standard rate, mobile charges vary)

**Textphone 0131 346 2529** (landlines charged at standard rate, mobile charges vary)

Provides advice and information on a range of disability issues, including cerebral palsy, housing and transport.

Open: Mon to Fri 9am-1pm

#### **Relationship and Stepfamily Helpline**

**0845 122 8655** (landlines charged at local rate, mobile charges vary)



Support and information to strengthen and improve your relationships and family life..

Open: Mon to Thur 12pm-4pm

### **Enquire**

**0845 123 2303** (landlines charged at local rate, mobile charges vary)

Advice on all aspects of education for children and young people with additional support needs.

Open: Mon to Wed, Fri 9am-7pm; Thurs 9am-7pm

### **NHS24**

**08454 24 24 24** (landlines charged at local rate, mobile charges vary)

Textphone: 18001 08454 24 24 24

For any concerns about your child's health, or the health of any family member.

Staffed by a team of nurses who offer information and advice, including information about local and national self-help and support groups.

Open: 24 hours a day, 7 days a week

### **Breathing Space**

**0800 83 85 87** (free from a landline, mobile charges vary)

If you're feeling down, depressed, worried or anxious and need to talk to someone during the evening or night call Breathing Space.

Open: Mon to Fri, 6pm-2am; weekends 6pm-6am

### **Samaritans**

**08457 90 90 90** (landlines charged at local rate, mobile charges vary)

Emotional support, for people who are experiencing feelings of distress or despair, including those which could lead to suicide.

Open: 24 hours a day, 7 days a week

### **Scottish Domestic Abuse Helpline**

**0800 027 1234** (free from a landline, mobile charges vary)

If you or someone you know is affected by domestic abuse, you can phone the Scottish Domestic Abuse helpline for information and support. Calls are answered by women with training in all aspects of domestic abuse. Records of calls will not appear on your phone bill.

Open: 24 hours a day, 7 days a week

### **Scottish Child Law Centre**

**0131 667 6333** (landlines charged at standard rate, mobile charges vary)

Gives advice on all aspects of Scottish law relating to the rights of children and young people, including parental rights and responsibilities, contact and residence, children's hearings and education.

Open: Mon to Fri, 9.30am-4pm

## Appendix 4: Consent Form

### Perceptions of being a parent of a child with an autism spectrum disorder

Researcher: [name given], Doctorate in Clinical Psychology, Postgraduate Student,  
University of Edinburgh

Please read each of the following statements carefully and then tick the box  
alongside to show that you agree. Please ask if you have any questions.

I confirm that I have read and understood the information  
sheet for the above study. ☐

I have had the opportunity to consider the information and  
ask questions. I have had any questions answered satisfactorily. ☐

I understand that my participation is voluntary and that I am  
free to withdraw at any time without giving any reason. A  
decision to withdraw will not affect the service I receive from  
[name of service], or any other services. ☐

I understand that my interview will be audio recorded and  
I agree to this. I am aware that the recording will be destroyed  
once the research is complete (approx. September 2013). ☐

I understand that the information from this interview, combined  
with that of other participants, will become part of a doctoral  
thesis, which will be written and published. ☐

I understand that mine and my child's identity will be protected.  
Pseudonyms will be used, with all identifying information  
removed from transcripts. ☐

I agree to take part in the above study. ☐

_____ Name of participant	_____ Signature	_____ Date
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_____ Name of researcher	_____ Signature	_____ Date
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Thank you for your help

## Appendix 5: Pilot Interview Schedule

Can you tell me what it has been like for you being a parent of a child with autism?

- How does it impact on daily life
- Family (other children and other parent/ extended family)
- Best/ worst things about it

What do you see as important to your role as \_\_\_\_\_'s parent?

- E.g. practically, emotionally, socially
- How do you see yourself as a parent? How has this changed over time?

What do you think impacts on/ affects **how you are** as a parent?

- E.g. can you think of experiences that you have had that have influenced how you parent

What do you think impacts on **how you feel** as a parent?

- E.g. can you think about experiences that you have had that have given you confidence/ made you doubt your parenting

### After the interview

Debrief:

- How was the interview?
- How did you feel doing it?
- Was there anything that you were wondering about? Any questions?
- Anything that I could do to make you more comfortable?
- Explanation of what happens next.
- Check if participant wants the results summary.

## Appendix 6: Full Interview Procedure and Schedule (revised post pilot)

### Pre-interview explanation

Me

No children and so no experience of being a parent

Trainee clinical psychologist, have worked in CAMHS services in other areas  
Board of Directors for [name of service], but have no involvement with service,  
therefore involvement will not positively or negatively affect your service. Any  
information used will be anonymised and is independent of [name of service], so  
won't discuss with the staff

Confidential except if concern re: risk

I'm interested in you and your story – what you think, feel and understand about  
what you have experienced

There are no right or wrong answers

Take your time to reflect

### Questions

Get info on demographic questionnaire/ Tell me about your child, what are they like?

- Tell me about your family

What can you remember about when your child was first assessed and diagnosed

- What was your reaction? How did that make you feel? How did that affect you as a parent?

Can you tell me what it has been like for you being a parent of a child with autism?

- How does it impact on daily life
- Family (other children and other parent/ extended family/ key relationships)
- What is the most challenging thing about being \_\_\_\_\_'s parent?
- What's the best thing about it?

What do you see as important to your role as \_\_\_\_\_'s parent?

- E.g. practically, emotionally, socially
- How do you see yourself as a parent? How has this changed over time?

What do you think impacts on/ affects **how you are** as a parent?

- E.g. can you think of experiences that you have had that have influenced how you parent

What do you think impacts on **how you feel** as a parent?

- E.g. can you think about experiences that you have had that have given you confidence/ made you doubt your parenting

What's the most important thing you have got out of/ learnt from being \_\_\_\_\_'s parent?

### Going deeper

- How?

- Why? In what way?
- Can you tell me more about that?
- Can you tell me about a recent example/situation where you thought/ felt that?
- Tell me what you were thinking?
- How did you feel?

#### After the interview

##### Debrief:

- How was the interview?
- How did you feel doing it?
- Was there anything that you were wondering about? Any questions?
- Anything that I could do to make you more comfortable?
- Explanation of what happens next.
- Check if participant wants the results summary.

#### Reflections

##### Key issues:

##### Reflections:

Context – how this might have affected process

What ideas were developed, suppressed and linked?

Were there any inconsistencies or puzzling links, threats to safety and how were they resolved?

Any larger discourses?

## **Appendix 7: Demographic Information Questionnaire**

Date of interview:

Name of parent (age):

Name of child (age):

Diagnosed with \_\_\_\_\_ when s/he was [age] \_\_\_\_\_ .

Educational placement:

Co-morbid conditions:

Other children (ages):

Other Parent:

Occupation:

### Appendix 8: Excerpt from coded transcript (P09)

Being a parent is an important role	<p>P: So your question is to tell you about Tim... Erm, Tim is our first child, and our only son. Erm, he was, er, born after, you know, I really always wanted to be a mother, so he was a great joy to me when he was born, and, erm, unfortunately he was quite ill in the first year of his life, he had pneumonia, and he had, erm, afebrile seizures, er, that means seizures without being associated with fever. And those seizures were ultimately deemed to be benign in nature, he's not epileptic, at least not yet, erm. However, we, understanding this more, that we now know more about autism, we suspect that those seizures were to do with his brain being an unusual brain. So he was quite ill at different times throughout the first year of his life, and that was obviously a very scary experience as a new parent, erm, but he recovered, erm, came out</p>	Importance of being a parent
Joy		Joy
Stresses		Early life, stressful, illnesses
Knowledge/ understanding about autism		Possible cause of autism or sign in hindsight
Meaning of autism – unusual brain		Autism as 'unusual brain'
Fear and worry		Fear and worry Identity 'a new parent'/ first born

Impact of being a new parent on knowledge, recognition and anxiety	of hospital, and was always, and is always a great joy to us. But I guess in really the second year of his life, erm, with hindsight, he was becoming more difficult, erm. I, as he was our first child, I didn't know what 'typical' behaviour would be, so I thought he was typical until I knew otherwise. And when I say he was difficult, he wasn't as co-operative as some other children might be, erm, and in between his second and third year, it was starting to be obvious that Tim was a bit different. It wasn't obvious to me at the time, but with hindsight it was obvious in that his, for example, his speech was very slow to develop, erm, although there's a wide range of what, young children, how they can speak, erm, but I guess that was the first indicator that, clear indicator, that he was an unusual child, erm, and by about the age of three, his behaviour was, erm, difficult enough for people to consider him to be a	Joy  Challenge (prefaced by joy)  First-born – reason for not picking up on problems    Difficult behaviour – compared to other children When first started to notice problems – different to other children   ‘Obvious’ – how can it be obvious if she didn't notice?   Slow speech as sign. Assumed that within the normal range Being a parent – awareness of the range  ‘Clear indicator’ as ‘obvious’ Autism as ‘unusual’  People consider him – perceptions of others of him being badly behaved
Challenge		
Difficult behaviour Compare your child with other children		
‘Obvious’ features that weren't seen at the time		
Being a parent – awareness of the range		
Meaning of autism - unusual		



Other people's criticism of the autistic child	badly behaved, inconvenient child. However, to us, he was always a complete joy. Erm, when I say he was difficult to manage, he would always do contrary things, like, when you carried him upstairs, he would immediately slide back downstairs,	and inconvenient Juxtaposed with 'complete joy to us' – comparing own feelings against others – contrary statements? As in Tim's apparently contrary behaviour
Child as joy	erm, but with great pleasure and	
Joy		Synonyms of joy

## Appendix 9: Example table of extracts and themes (P02)

Themes	Extracts	Line number
<b>A: Experiencing autism as hard to know</b>		
<ul style="list-style-type: none"> <li>Hard for parent and others to recognise and understand</li> </ul>	<i>You can feel sometimes, and I feel this, I can feel like, ‘well, did she get anything out of that at all? Was that a complete waste of time? Did she even notice? Did she even, what did she think about it?’</i>	918
<b>B: Experiencing autism as all-consuming and extreme</b>		
<ul style="list-style-type: none"> <li>i) Autism impacting on everything</li> </ul>	<i>...if Rachel’s there, you’re always having to hold her hand, you’re always having to watch her, you can’t do, you know, it really restricts what you can do and it can turn something that should be fun into something that’s a chore, you know. I mean, it is just not fun sometimes, taking her certain places.</i>	192
<ul style="list-style-type: none"> <li>ii) Parenting autism as an impossible task</li> </ul>	<i>And I’ve experienced a few times, you know, I’ve actually had, you know, I’ve been taking care, and trying to keep her under control and that, and all she’s done is, she’s interested in people, she doesn’t do anything bad, yes, she’s curious, she’ll come up and, if she was here now she’d be looking at your necklace and stuff, you know.</i>	154
<b>C: Diagnosis giving understanding and confidence</b>		
<ul style="list-style-type: none"> <li>i) Making changes and doing something</li> </ul>	<i>Actually, when she was diagnosed, it made everything easier for us because she could be, we could start going down the correct channels, and she’d be getting the right, she’d be in the system, you know.</i>	393
<ul style="list-style-type: none"> <li>ii) Reducing blame and building</li> </ul>	<i>I say, sorry, you know, I often apologise. Er, I find it funny as well, I</i>	177

confidence	<i>sometimes, we end up, sort of chatting and stuff, but I apologise and say my daughter has autism, or is autistic. You know, she's just, sort of, you know, she's just interested in everything.</i>	
<b>D: Parenting in the eyes of others</b>		
<ul style="list-style-type: none"> <li>i) Criticism and judgement of child and parent</li> </ul>	<i>It's just difficult, you know. Erm, you know, I mean, little girl, running up to a bunch of people sitting down and that, and sort of, just pouncing, you know, er, through in there, and sort of wondering, where's the mum, where's the dad? You know, why is this child coming over here? I can only imagine, I mean, its going to get a bit more worse as she gets older and bigger. You know, I mean, are we going to have, like fourteen-year-old daughter who's like, you know, I mean, sort of acting inappropriately and stuff.</i>	212
<ul style="list-style-type: none"> <li>ii) Recognition and evidence of parenting skills</li> </ul>	<i>She's, if she didn't like, if she doesn't like something, she will let you know. She doesn't have any problem coming down here, and she's always glad to see me, and you know, both me and her mum agree that she's, you know, she must enjoy coming down here and seeing me.</i>	625
<b>E: Dilemma of acceptance</b>		
<ul style="list-style-type: none"> <li>i) Acknowledging pain and loss</li> </ul>	<i>Yeah, having a daughter who's disabled, you know, and not what, you know, when we had kids, that wasn't what I thought having children would be all about. You know, I wasn't expecting that. And one of my worst fears was something like that, sort of happening.</i>	294
<ul style="list-style-type: none"> <li>ii) Oscillating between fear and hope for the future</li> </ul>	<i>I think she does have a pretty good life, you know. You know, and that's what, sort of, concerns me most, you know, if I knew she was un..., unhappy, and stuff, you know, I'd probably just, you know, I, it might just be her, or just her life, you know, but I sort of see her most of the time as being an, enjoying herself, happy and stuff, you know.</i>	958

<ul style="list-style-type: none"> <li>iii) Meanings of acceptance</li> </ul>	<i>There is a lot of positive things with her, you know, there really is a lot of positive stuff with her, you know. We don't go around, sort of, you know, you have to be, you don't go around, sort of, er, upset. We just get on with it, you know, really, you know, just get on with it.</i>	595
<ul style="list-style-type: none"> <li>iv) Finding positives and discovering rewards</li> </ul>	<i>You know, it's probably actually been good for us in our lives, you know, its probably done us some good, you know, cos probably took quite a few things for granted beforehand.</i>	530

## **Appendix 10: Excerpt from Reflective Diary**

Reflective diary 28<sup>th</sup> November 11

Pre- interview P06

Was thinking about this question of why autism? Why is it important? I think this is a different question to how I am interested in it, i.e. my work experience journey into this. Children with autism can be the most challenging to manage and to parent, in terms of their behaviour, but also the real distress from being around a person who is so different socially, who you struggle to understand, and know why they behaved in a certain way. Also challenging when social interaction is so highly valued by our society and culture. That they seem to do things that really hurt us, but don't mean it, not trying to hurt us (e.g. P05 child protection incident). The number of families referred to CAMHS, LD services, autism over-represented? Also don't look like they have a disability, look, in one parent's words, more beautiful than other children, and that it's an invisible disability, making it even harder to understand why they are behaving the way they are. As well as from other people's point of view, not recognising that the child has a disability, therefore producing those stares, parents feel judged, blamed, as it looks like a child being naughty.

Post P06 interview

I think this relates to a question as to why it is relevant for clinical psychology. I guess IPA is a psychological approach, about meaning making and appraisals which are psychological processes. And it seems that key to this whole experience is how a parent makes sense of this, and this has a profound impact on how they cope. And even if I only speak to the people who are making sense of it and are coping (as a product of my research design and sampling) this is still a helpful process. In a positive psychology perspective, like recovery approach discussed in the psychosis teaching last week, looking at what helps/ when its going well. So these may precisely not be the people who come to CAMHS because they are coping, which means that we don't see them and learn from them. This came to mind precisely because in spite of huge challenges, P06 recognised that she was resilient.

I was also pleased to hear that she had had such a positive experience of a clinical psychologist. Must remember to be careful of her fear – professionals coming along to tell parents how to manage their children. Parents want to be listened to – they are the experts on their child.

I came out of this interview feeling more positive – I think because I could see her making sense of her experience, and I could make sense of that! Though at the end I did not manage to keep myself from falling into clinician mode – have you tried OT? Sensory diets etc., should read more myself about that.

Key issues for this mum – negative experience of services, perhaps a motivation to participate, to improve the way professionals work/ communicate with families. This child had complex issues beyond autism, making an already challenging condition even more so. It also struck me how important it was to have people around who were positive, having aspirations for your child, and seeing their potential, and seeing them as a person/ personality. She was quite tearful as she described it as

‘horrendous’, and although I tried to prompt, she did not describe this further, and I didn’t want to push it. I think that was appropriate.

## **Appendix 11: Summary of Findings sent to Participants**

Email:

Dear \_\_\_\_\_,

I hope that you and your family are well. I am writing to thank you for taking the time to be interviewed for my research, back in November/ December last year. Your participation was very much appreciated. I was humbled by all my participants' honesty, generosity and willingness in sharing what were sometimes very difficult experiences.

I am now reaching completion of my thesis, and have attached a summary of what I found for you to read. I have tried to keep it short, and I hope that it makes sense to you. I would be interested in any comments that you feel you would like to make, or any questions you might have about the results or about what I did. You can contact me by email or phone. If you would like a copy of a journal article I am preparing on the work, please ask.

Thanks again for taking part, and I wish you all the best for the future.

Yours sincerely

## **Experiences of autism and perceptions of parenting in parents with a child with autism**

### **Summary**

Previous research has highlighted that parenting a child with autism can be challenging and stressful. However, there is less known about the parental perceptions of this experience and processes of adjustment. Nine parents of children with autism were interviewed about their experiences of being a parent, and their perceptions of themselves. The interviews were transcribed, all names were changed and the data were analysed. Five over-arching themes were found, summarised in the diagram above and discussed below. Each of these themes was felt to capture the experiences of the majority of parents who participated, but it was acknowledged that these were not representative of all parents with a child with autism.

### **A: Experiencing autism as hard to know and understand**

Parents spoke of the difficulties they had experienced because the condition of autism is hard to identify, recognise and diagnose, and this often had an impact on their sense of self as a parent. Even after diagnosis, they described challenges around the ‘invisibility’ of autism, in that children do not look like they have a disability or developmental condition, and so their behaviour can be misunderstood by their family and the wider society. They also talked about the challenges of connecting with and understanding their child in the context of autism.

“...as he was our first child, I didn’t know what ‘typical’ behaviour would be, so I thought he was typical until I knew otherwise. And when I say he was difficult, he wasn’t as co-operative as some other children might be, erm, and in between his second and third year, it was starting to be obvious that Tim was a bit different. It wasn’t obvious to me at the time, but with hindsight it was obvious.” (P09)

“He, he didn’t even answer to his name. I used to think, have I given the wrong name? Maybe he wants another name.” (P08)

“I think that’s the problem with what, autistic children is, they’re actually, the majority of them are very, very pretty children, they’re, they’ve got quite good looks, so they just look, they look like they’re fine, so I guess that’s why people stare so much, they think they’re just bad.” (P04)

### **B: Experiencing autism as all-consuming and extreme**

The second over-arching theme captured the participants’ experience of autism as being all-consuming, demanding and impacting on all aspects of family life. Across all interviews, parents discussed how extreme and relentless the condition could be, providing many challenges, with the child requiring constant and vigilant attention. This characteristic led to a sense that parenting children with autism was an impossible task; that despite all the efforts made, they and their child still struggled, and their parenting did not always achieve the outcomes they hoped for. This impacted on their sense of self as a parent.

“It’s extremely tiring, and [2], well it’s actually chronically tiring, I think that’s a good description of it, it’s chronically tiring, there is no let-up from it, there is no day that is any easier than another day,



erm, in terms of his behaviour. Some days are more aggressive, erm, and obviously some days are more fun, but they're equally difficult to get through." (P09)

"I think when, when he's younger, you just, sort of, deal with it, but I'm finding now, as he's getting a bit older, and we're still dealing with it, but I think about more how long I've been dealing with it, and how it's not really much better, and is it always going to be like this?" (P06)

"I used to think, maybe two or three years ago, I used to think, yes, I will find the key [laughs]. I will unlock the challenges, you know, I'll find the formula, and I will be able to, 'no, forget about it, you can't do that'. And I learnt a lot actually, from watching [his worker], how she worked with him and so on, beginning to understand that a) it's a very, very long process, and there's no, there's no real epiphanies with autistic children, or eureka moments, not really. Or if they do have an epiphany, it's over a week, you know." (P08)

### **C: Diagnosis giving understanding and confidence**

The third over-arching theme captured the parents' experiences of the positive consequences of having a diagnosis of autism for their child, in spite of all the challenges. Although recognising the condition and having it professionally identified often took time, participants described how having diagnosis helped them to make sense of their children's difficulties, understand them better, and make positive changes in how they responded to them in order to support them. For many parents, it also reduced the sense of blame they had been feeling about their child's problematic behaviour, and gave them more confidence in their parenting skills.

"To deal with it, I feel like I am, you know, was equipped with strategies how to deal with it, while before, I just know that he has autism, but no support, or, and you know, just reading, reading on the internet, doesn't really [S: you need more than that]. Yeah, you need really to, you know, like, with [Service A], it was, er, it was Jane, you know, the nursery nurse, that, you know, she was showing me, so when you go, look how I will, and I could really see how, how change, you know, Freddy's behaviour and he stop it, and [2] yeah, so. So then I seen that yeah, it's working." (P05)

"I started trying to adapt to those strategies straight away, and that made..., it just helped me understand Connor a little bit more. Erm, and yeah, it was like this huge, 'it's not my fault, I didn't...', that I'm not doing something wrong." (P03)

### **D: Parenting in the eyes of others**

The fourth theme of 'parenting in the eyes of others' emerged through the participants' recollections of being negatively judged or positively recognised for their parenting, at both a real and an imagined level. Many participants talked about dealing with other people's reactions to their child and judgements on their parenting as one of the most challenging aspects of their parenting experience. The difficulties in recognising the condition of autism often created situations where the child was criticised for their behaviour by their nursery or by the public

"Er, you know, I've had people say to me, only once or twice, [this town]'s not bad, you know, 'you need to take more control of your kids, or your daughter'. And I'm like 'sorry', I mean, you know, I'm thinking, can you not tell there's something a wee bit amiss with her, you know." (P02)

"...as the mother of a badly behaved child, instead of being the caring mother of a delightful child, I was gradually becoming a bad parent of a badly behaved child, so I faced a lot of personal criticism and hostility as a result of Tim's condition and my health has suffered significantly, my mental health

has suffered significantly as a result, erm, and continues to suffer, although I now have a greater understanding of autism and also depressive illness, erm, but that is the reality for me. People quite often have, erm, condemned Tim, and me, and that is obviously not, not a good feeling. Erm, however unjustifiable, it's still hurtful." (P09)

The second aspect to 'parenting in the eyes of others' was the sub-theme of feeling positive when parents' ability and efforts were recognised by others (e.g. school, nursery, friends or relatives), or validated by the child making progress.

"I think it makes a huge difference if you know that other people like your child." (P03)

"I think I'm a good parent. People tell me I'm a good parent, so, but I do worry, you know. I perhaps don't worry so much now as I used to, because I've seen him progress. I used to worry that he wouldn't progress, that really did frighten me. But, erm, I've, you know, he's been alive long enough now, for me to realise that, yes, he will get there eventually." (P08)

## **E: Dilemma of acceptance**

The final theme captured the ongoing dilemmas parents experienced around accepting the condition of autism in their child. On the one hand, accepting autism meant acknowledging the pain it had caused, and the loss this meant for them and their family both in the present and for the future. On the other hand, it enabled them to reflect on how the experience had affected them positively and what their family had gained from it.

Some participants spoke of experiencing emotional pain and loss on learning their child had autism, and in coming to terms with the implications of this. Although this theme did not arise in all interviews, it was strongly expressed in those that it did occur. Some parents used a metaphor of physical pain to describe the feeling. They talked of a "massive blow" (P09), feeling "mortally injured" (P09), and being "like a punch in the stomach" (P06).

"But there are times, that's what hits you, that's when I do get those days when, maybe just a little thing can happen, and you just think, oh, that's, our child's never going to be able to do that, or we're never going to be, experience that with our child or that. But usually I try and, usually we sort of try and turn it round to, 'well maybe that won't happen but this can happen or a different version of this', you know, because I think that's a more positive way of looking at it. But there are days when you're just not positive." (P06)

The sub-theme of 'oscillating between fear and hope for the future', captured the participants' expression of their fears and worries for their child's future juxtaposed with hope and cautious optimism that they and their child could cope.

"But I do also feel at this time in his life that, I still feel like I'm in the unknown, you know. I don't know what's going to, I don't know how it would be when he's a teenager, or older, or what, you know. [2] But I worry less about it now, you know, we'll work it out, whatever happens, we'll, we'll cope, you know. I don't think, well, I don't think he'll, I think he will go on and get a job and so on, but, I don't think anybody who's in the process of supporting him now should stop doing what they're doing, because I think if they did, it would be a completely different story. (P08)

The sub-theme of ‘meanings of acceptance’, encompassed the spectrum of ways that acceptance was expressed by the parents. This ranged from finding autism difficult to acknowledge, towards a sense of resignation and tolerance, through to open and unconditional acceptance of the child. As with the above sub-themes, participants moved between these states throughout the interviews, illustrating acceptance as an ongoing process rather than an end point or absolute outcome.

“But that said, do you know if, but that’s what, kids are kids, you make the best of what you have, it just so happens that our kids are quite demanding, and we just have to work round it. It won’t be forever, well, it might be, erm, we just have to wait and see.” (P07)

The final sub-theme represented the participants’ discussion of the benefits and positive outcomes of their experience of parenting a child with autism.

“It’s quite nice to appreciate the little things, like Michael when he first said ‘Mum’. That meant more when he said ‘Mum’ when he was five than it would have done when he was one, if that makes any sense, because there was more meaning to it.” (P07)

“I think Gill has, erm, Gill has probably helped me become a less stressful person, because, as I say, she makes you take the time to stop, and, and you do, you think, well there’s far more important things, like, so what. And like that’s possibly what, what’s helped me become less stressed and, because I would always, I would be ill for months thinking about things like that before, but not with her, no, I think she’s shown me something different. I think she’s taught me a lot more than I could ever teach her, definitely, definitely, she’s taught me more.” (P04)

“He’s completely unbridled in his joy of life. Erm, and so when he’s happy, I’m happy, [crying] and often when he’s unhappy, I am not happy, not always because I understand that really there’s not, I can’t solve all of his problems, so he, he is at the same time, the light and the darkness of my life. But mainly the light.” (P09)

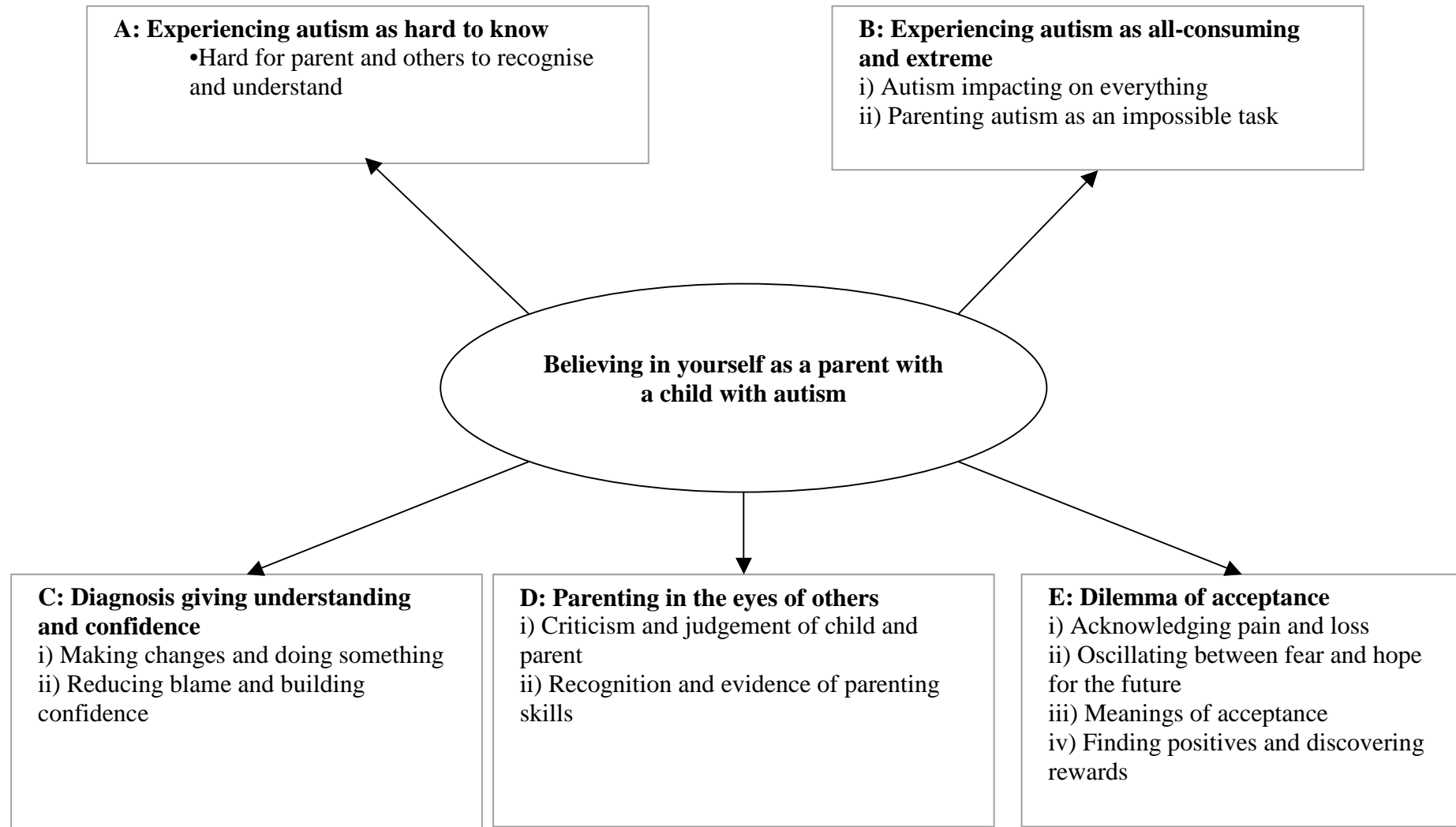
## **Conclusions**

This research has provided a richer understanding of self-perceptions of parenting and the impact of the experiences of being a parent with a child with autism. It has contributed to a broader literature on positive adjustment in families with a child with autism.

The findings are relevant to those working in autism assessment and diagnostic services, as well as those directly supporting and providing interventions to families with a child with autism. Feedback on the results will be given to the services that I work with. I hope to disseminate the findings more widely through the publication of a journal article.

## Experiences of autism and perceptions of parenting in parents with a child with autism

The following diagram outlines the main themes and sub-themes found in the study.



## **Appendix 12: Author guidelines for the journal *Autism***

### ***Manuscript Submission Guidelines***

#### ***Autism: The International Journal of Research and Practice***

*Autism* provides a major international forum for research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders.

#### **1. Peer review policy**

*Autism* operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. *Autism* strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection. Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

#### **2. Article types**

The Journal considers the following kinds of article for publication:

1. Research Reports, describing new experimental findings;

(a) *Full papers*

(b) *Short reports requiring rapid dissemination* (2,000 words maximum, no more than 2 tables and 15 short references)

2. Review Articles. The Editors wish to encourage the following types of review, but request that authors contact them in advance:

(a) *general reviews that provide a synthesis of an area of autism research;*

(b) *critiques - focused and provocative reviews that are followed by a number of invited commentaries, with a concluding reply from the main author;*

3. Letters to the Editors. Readers' letters should address issues raised by published articles or should report significant new findings that merit rapid dissemination. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

Full papers are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract, notes, references, tables, biographical statement, etc.). We are reluctant to burden our referees with very long manuscripts. Editors may ask authors to make certain cuts before sending the article out for review.

### **3. How to submit your manuscript**

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

*Autism* is hosted on SAGEtrack a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/autism> to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit [ScholarOne Online Help](#).

All papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

### **4. Journal contributor's publishing agreement**

Before publication SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit our [Frequently Asked Questions](#) on the SAGE Journal Author Gateway.

#### **4.1 SAGE Choice**

If you wish your article to be freely available online immediately upon publication (as some funding bodies now require), you can opt for it to be included in SAGE Choice subject to payment of a publication fee. The manuscript submission and peer reviewing procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing SAGE Choice. For further information, please visit [SAGE Choice](#).

### **5. Declaration of conflicting interests**

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. *Autism* does not require a declaration of conflicting interests but recommends you review the good practice guidelines on the [SAGE Journal Author Gateway](#).

### **6. Other conventions**

We would prefer to use the term 'people with autism' or 'people with autism spectrum disorders or conditions'. We would also prefer the term 'typically developing' rather than 'normal'.

### **7. Acknowledgements**

Authors are encouraged to acknowledge the support of the funders of their research.

Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

### **7.1 Funding Acknowledgement**

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), *Autism* additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. All research articles should have a funding acknowledgement in the form of a sentence as follows, with the funding agency written out in full, followed by the grant number in square brackets:

This work was supported by the Medical Research Council [grant number xxx].

Multiple grant numbers should be separated by comma and space. Where the research was supported by more than one agency, the different agencies should be separated by semi-colon, with "and" before the final funder. Thus:

This work was supported by the Wellcome Trust [grant numbers xxxx, yyyy]; the Natural Environment Research Council [grant number zzzz]; and the Economic and Social Research Council [grant number aaaa].

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### **11. Further information**

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office as follows:

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